OVERVIEW OF DISPARITIES IN CARE AND OUTCOMES IN DIVERSE PARKINSON DISEASE POPULATIONS

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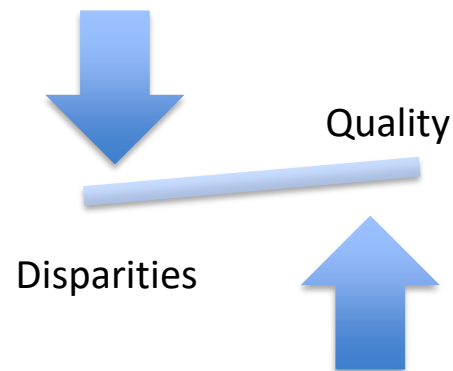Strength in optimism. Hope in progress.

DISCLOSURES

I have received support from:

- NIH
- Parkinson Council
- Parkinson Foundation (formerly NPF and PDF)
- Michael J. Fox Foundation
- AbbVie
- Roche, Ely Lilly and Cala Health (site PI for clinical trial)
- Medtronic (training grant)
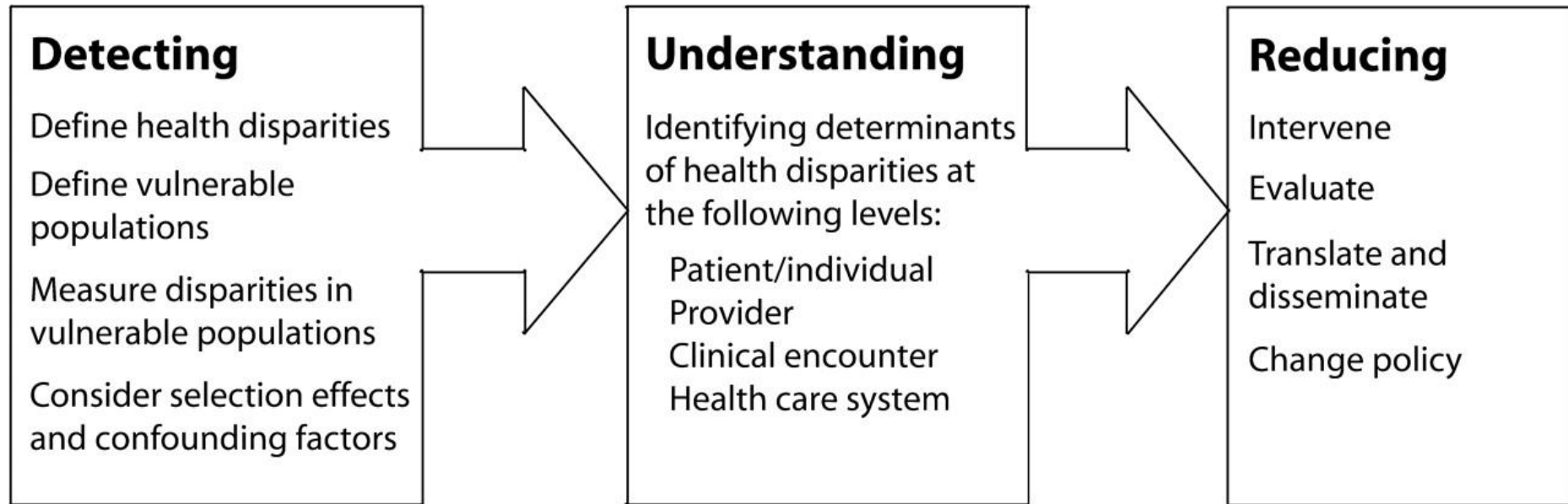- Acadia (advisory board)

UNDERSTANDING GROUP DIFFERENCES IMPROVES CARE

1. Increased understanding of underlying physiology of disease and development of treatment

2. Reduce variability in care due to non-biological factors and improve quality

Quality

Disparities

3. Social justice and reducing inequalities

Detecting

Define health disparities

Define vulnerable populations

Measure disparities in vulnerable populations

Consider selection effects and confounding factors

Understanding

Identifying determinants of health disparities at the following levels:

Patient/individual
Provider
Clinical encounter
Health care system

Reducing

Intervene

Evaluate

Translate and disseminate

Change policy

Kilbourne, A. M. et al. Am J Public Health 2006;96:2113-2121

DIFFERENCES -- BIOLOGICAL

Group differences in incidence, prevalence, morbidity and mortality of disease

DISPARITIES -- SOCIAL

Group differences in the quality of healthcare or treatment that are not due to clinical needs, preferences, and appropriateness of intervention (*Institute of Medicine, Unequal Treatment*)
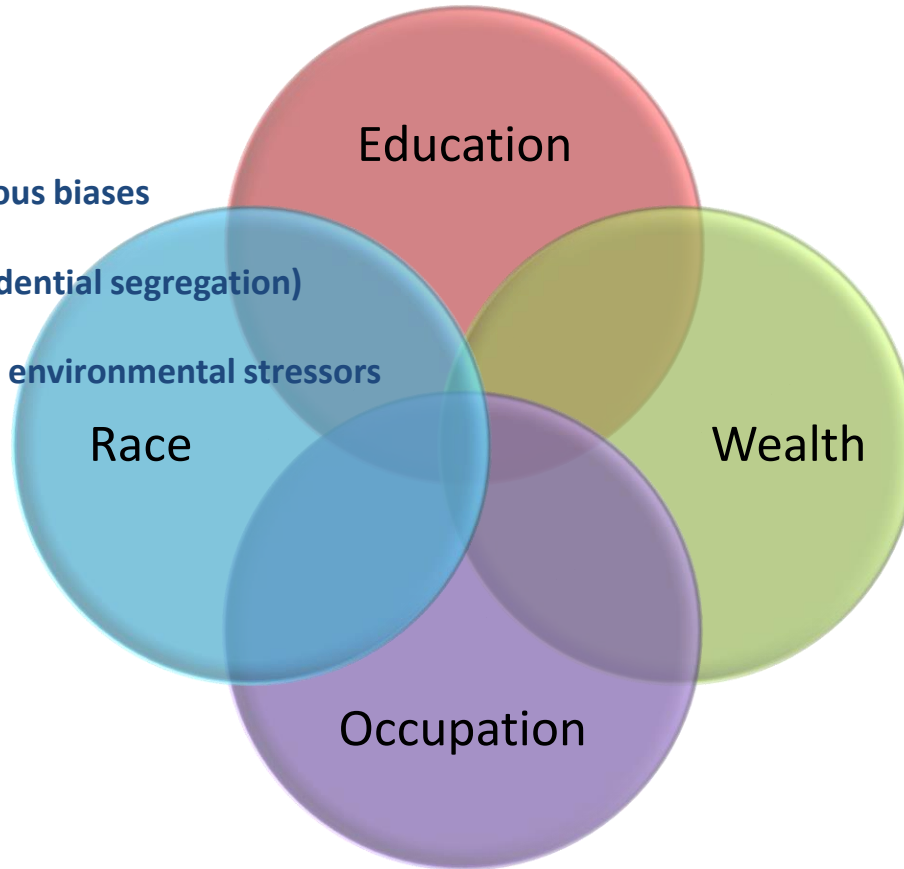
Group	Biology	Social
Sex	Characteristics encoded in DNA such as reproductive organs and other physiological traits (e.g. sex hormones)	Social, cultural and psychological traits linked to men and women through social context = gender
Race/ ethnicity	More genetic similarities between races/ethnicities and no genetic feature that is entirely unique to any race/ethnicity However, using socially-constructed definitions for race/ethnicity, there are allelic variations in disease risk, severity and responsiveness to treatment that partly explain racial/ethnic differences. For example, African-American women and breast cancer mortality	

Discrimination and unconscious biases

Institutional racism (e.g. residential segregation)

Higher exposures to multiple environmental stressors

4 identical clinical presentations of chest pain presented to cardiologists at national meeting with corresponding patient picture

TABLE 5. PREDICTORS OF REFERRAL FOR CARDIAC CATHETERIZATION.*

MODEL AND VARIABLE	ODDS RATIO (95% CI)†	P VALUE
Race and sex as separate factors		
Sex		
Male	1.0	
Female	0.6 (0.4−0.9)	0.02
Race		
White	1.0	
Black	0.6 (0.4−0.9)	0.02
Interaction of race and sex		
White male	1.0	
Black male	1.0 (0.5−2.1)	0.99
White female	1.0 (0.5−2.1)	>0.99
Black female	0.4 (0.2−0.7)	0.004

Schulman KA, et al. NEJM. 1999; 340: 618-26.

BLACKS HAVE LOWER DIAGNOSED PREVALENCE AND INCIDENCE OF PD

Prevalence per 100,000 persons
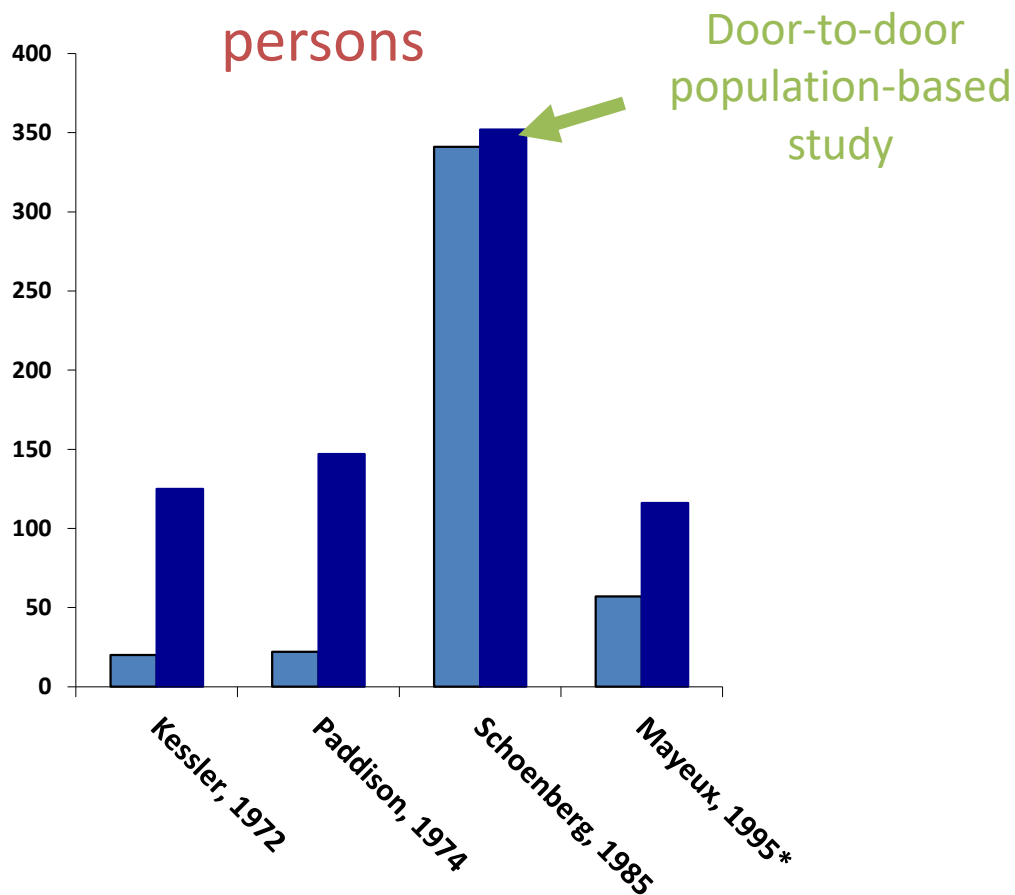
Incidence per 100,000 person-years

Door-to-door population-based study

Kessler, 1972
Paddison, 1974
Schoenberg, 1985
Mayeux, 1995*

Mayeux, 1995
Van Den Eaden, 2003
Dahodwala, 2009

Dark blue = Whites, Light blue = African-Americans; *age-adjusted estimates

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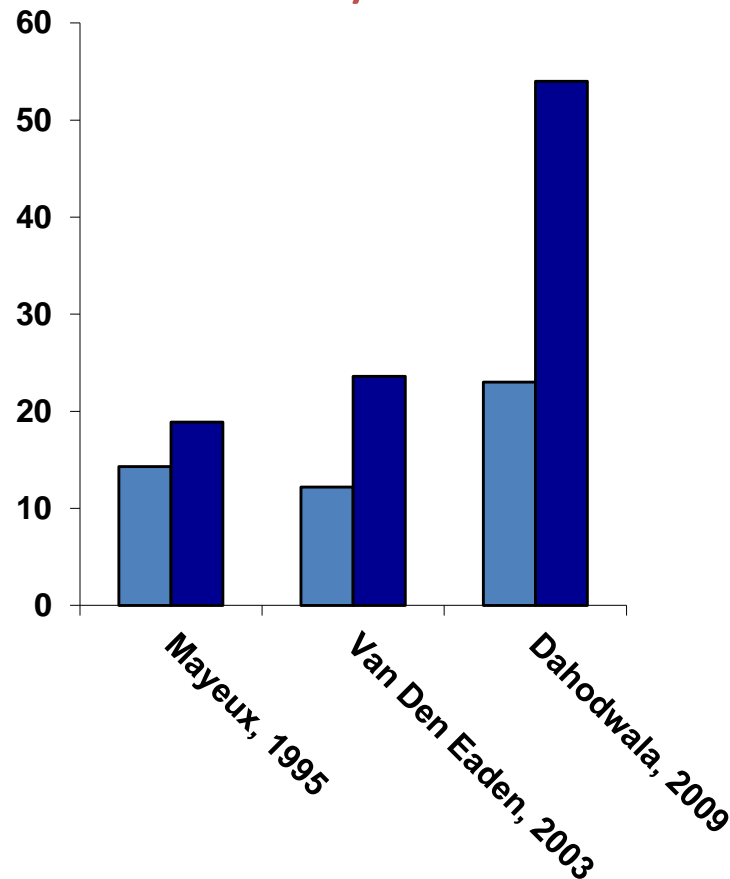
POTENTIAL EXPLANATIONS FOR RACIAL DIFFERENCES IN PD EPIDEMIOLOGY

1. Biological

   - Melanocortin1-receptor Arg151Cys polymorphisms and black < brown < blonde < red hair associated with risk of PD

   - Higher serum 25-hydroxyvitamin D levels associated with decreased risk of PD

2. Social

   - Missed and delayed diagnoses

   - Differences in health literacy

   - Historically limited access to care

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Gao X, et al. Ann Neurol. 2009; 65: 76-82; Knekt, et al. Arch Neurol. 2010; 67: 808-11
Schoenberg B, et al. Neurology. 1985; 35: 841-845.

MISSED AND DELAYED DIAGNOSES OF PD

Door-to-door populations-based study in Mississippi:

- ~40% of *prevalent cases of PD* were previously undiagnosed
- Twice as many African-Americans were undiagnosed as whites

Study of *new diagnoses of PD* presenting to Philadelphia VA

- African-Americans had an increased odds (OR 3.31) of presenting for care at later stage of disease than whites
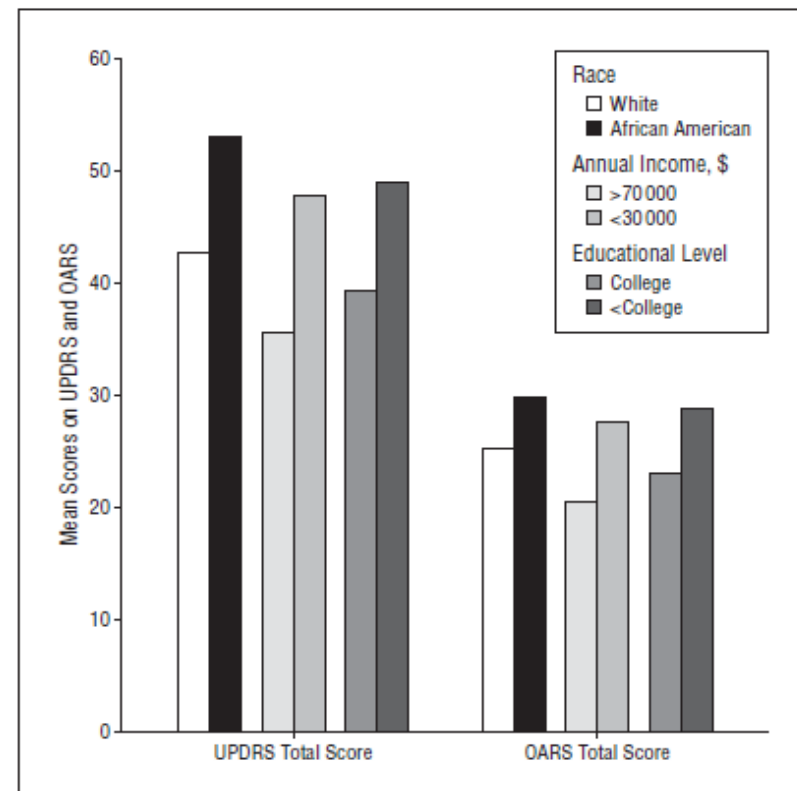
Study of *first visit to specialist* in Baltimore

- Worse motor scores and greater disability among African-Americans

Schoenberg B, et al. Neurology. 1985; 35: 841-845.
Dahodwala N, et al. Neuroepidemiology. 2011; 36: 150-4.
Hemming JP, et al. Arch Neurol. 2011; 68: 498-503.

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➢ Perception of disability

- **Self-reported disability does not always correlate with clinician observed impairment**

➢ PADRECC cohort of newly diagnosed PD cases (N=74)

➢ Calculated difference between standardized:

- **UPDRS Part 2 - self-reported disability → SUBJECTIVE**
- **UPDRS part 3 - motor examination → OBJECTIVE**

➢ If difference was negative, then under-reporting of symptoms relative to motor impairment

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Shulman LM, et al. Mov Disord. 2006; 21: 794-799

Leritz E, et al. Clin Neuropsychol. 2004; 18: 352-361

COMPARISON OF SCORES ON SELF-REPORTED DISABILITY VS. MOTOR IMPAIRMENT BY EXAMINATION

Dahodwala N, et al. Neuroepidemiology 2011; 36: 150-4.
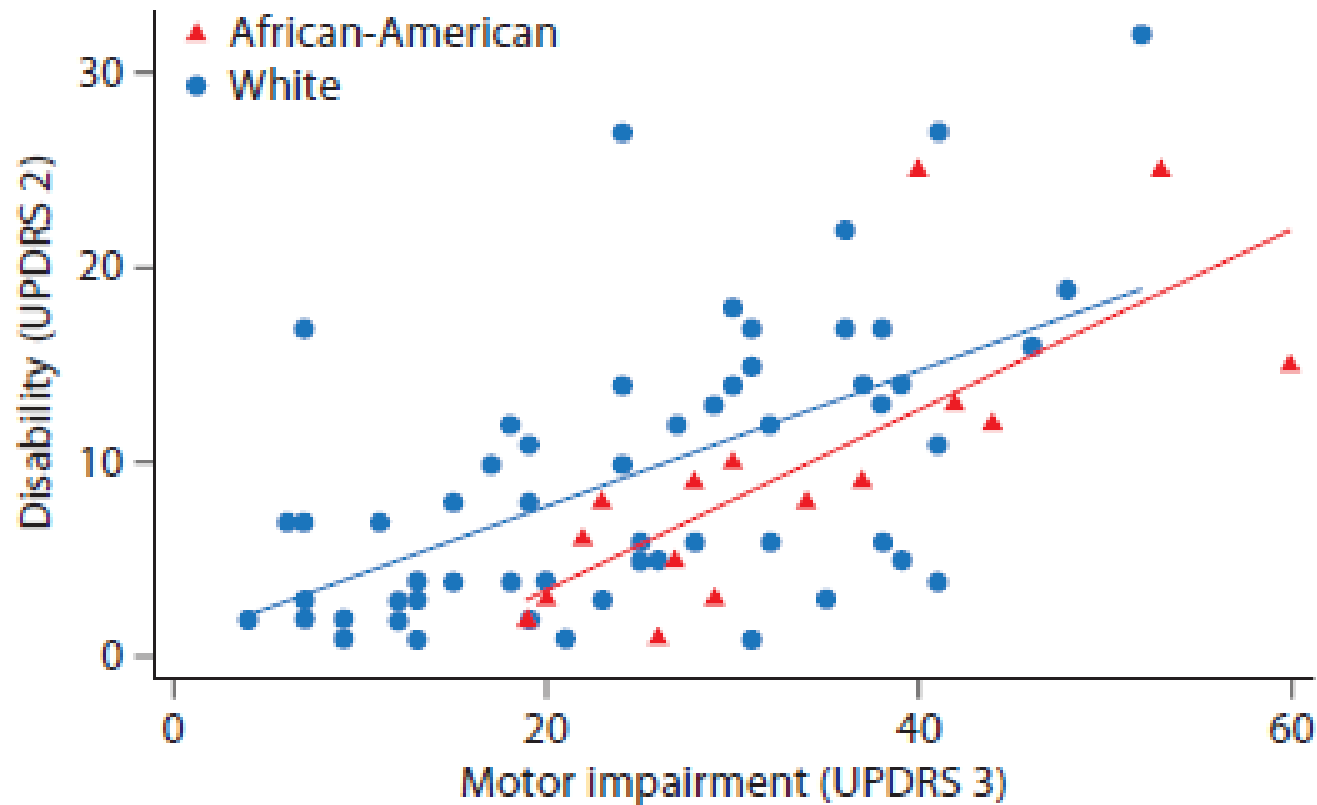
HEALTH LITERACY

- Capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions

- 35-80% of older adults have inadequate or marginal health literacy.[1]

- Associated with poorer self reported health, higher hospitalization rates, higher mortality than in age matched controls.[2,3,4,5]

1. Baker DW et al. JAMA 2007:167(14):1503-1509; 2. Baker DW et al J Gen Intern Med 1998;13(12)791-798; 3. Sudore RL et al. J Gen Intern Med 2006;21(8)806-812. 4. Gazmararian JA et al. Patient Educ Couns 2003;51(3):267-275. 5. Williams MV et al Chest 1998;114(4):1008-1015.

HEALTH LITERACY IN OUTPATIENT NEUROLOGY

- Administered Short Test of Functional Health Literacy in Adults (S-TOFHLA) to 201 outpatient neurology patients

- Prevalence of low health literacy was 20.5%

- 26% of all subjects were unaware of any of their neurologic medications

- Influence of race and SES on odds of low health literacy:

Factor	Unadjusted OR	Limited model OR (without education)	Full model OR (with education)
African-American race	3.21 [1.46-7.03]	2.73 [1.08-6.95]	2.06 [0.77-5.50]

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Fleisher J, et al. Neurol Clin Pract. 2014; 4(1): 71-81.

- Mixed methods study
  1. **Qualitative: Focus groups**
  2. **Quantitative: Survey of knowledge and beliefs**

- Recruited members of local senior centers in three race/ethnic communities
  1. **West Philadelphia, West Oak Lane – African American**
  2. **Chinatown – Chinese**
  3. **South Philadelphia – White**

- Principal aims to determine level of PD-specific knowledge (symptoms, causes and treatments), attitudes and barriers to care

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BARRIERS TO PD CARE: RACIAL/ETHNIC DIFFERENCES FROM PHILADELPHIA SENIOR CENTER FOCUS GROUPS

Similarities among all:	Differences between:		
	African-American (N=36)	Asian (N=16)	White (N=23)
Denial There is little you can do for PD	Lack of insurance Mistrust – "turn you into an experiment" Some religions against going to the doctor	Language barrier Would not know where to go	Not aware that they have it

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Pan S, et al. J Cross Cult Gerontol. 2014; 29(3): 339-52.

J Cross Cult Gerontol

Table 4 Percentage of participants correctly answering PD knowledge items

Knowledge item	African-American (n=47)	Chinese-American (n=45)	White (n=62)	Support group member (n=52)	p-value
More common in elderly	44.7	46.7	46.8	75.0	<0.01
Blood test is available	17.0	13.3	8.1	84.6	<0.01
Cause unknown	38.3	28.9	43.6	69.2	<0.01
Contagious	57.5	37.8	62.9	100	<0.01
Tremor is main symptom	48.9	51.1	54.8	71.2	0.10
Memory loss is main symptom	29.8	15.6	25.8	51.9	<0.01
Slowness is main symptom	48.9	46.7	43.6	78.8	<0.01
Medications help symptoms	63.8	33.3	59.7	90.4	<0.01
Exercise helps symptoms	46.8	42.2	37.1	98.1	<0.01
Diet helps symptoms	19.1	13.3	12.9	13.5	0.79

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Pan S, et al. J Cross Cult Gerontol. 2014; 29(3): 339-52.

Geographic disparities

- Movement disorder specialists tend to practice in large, urban centers

- Impaired mobility and cognition from PD make travel to specialists office even more burdensome

ACCESS TO NEUROLOGIST IN THE US

Randomized controlled trial of virtual house call
- No improvement in QOL, caregiver burden or quality of care
- 98% of participants randomized received visit (feasible)
- Average 88 minutes and 38 miles of travel saved (convenient)

Figure 2 Proportion of M... who do not rece...

Percentage without neurologist care
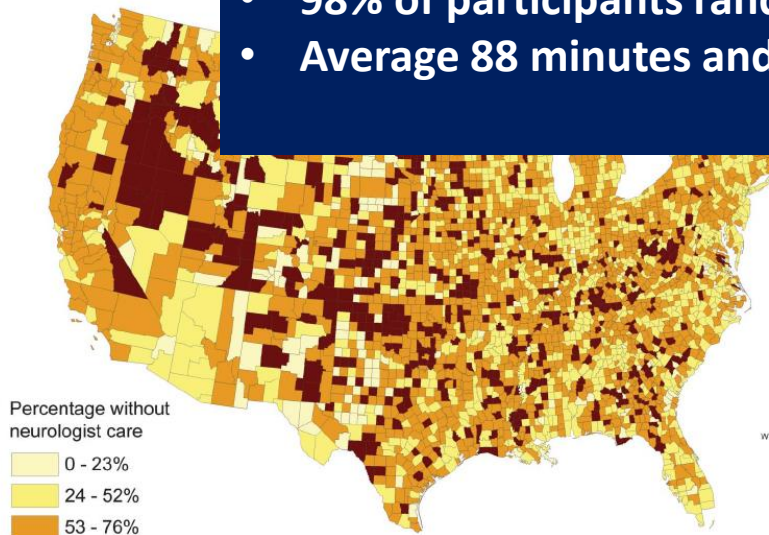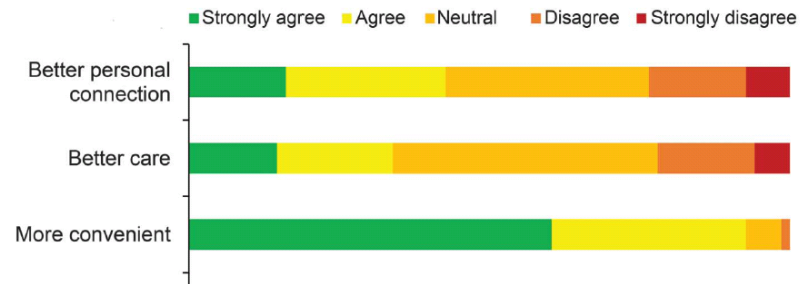- 0 - 23%
- 24 - 52%
- 53 - 76%

Figure 3 Participants' relative preference of virtual house calls with remote specialist vs in-person visit with usual Parkinson disease provider across different dimensions (n = 68)

■ Strongly agree ■ Agree ■ Neutral ■ Disagree ■ Strongly disagree

- Better personal connection
- Better care
- More convenient

1. 73% had already seen a specialist; 74% college-educated
2. 96% used internet/email

(for context, among older adults earning <$30,000/yr: 39% use internet/email and 25% have broadband connection)

Dorsey ER, et al. Neurology 2013; 80: 1989-1996
Beck CA, et al. Neurology 2017; 89: 1152-1161

- Accuracy of PD diagnosis among physicians ranges from 76-91%

- Sensitivity for other parkinsonian disorders ranges from 25-100%

- Uncertainty in diagnosis will lead to variable detection

Hughes AJ, et al. Brain 2002; 125: 861-870

REFERRAL TO NEUROLOGICAL CARE

- Among Medicaid patients, 33% of African-Americans and 39% of whites with PD were initially seen by a neurologist

- In a Medicare population, African-Americans with incident PD were significantly less likely to be referred to a neurologist (OR 0.76, 95% CI 0.72-0.79)

Dahodwala, et al. Ann Neurol 2009; 66: 142-145
Willis AW. Neurology 2011; 77:851-857;

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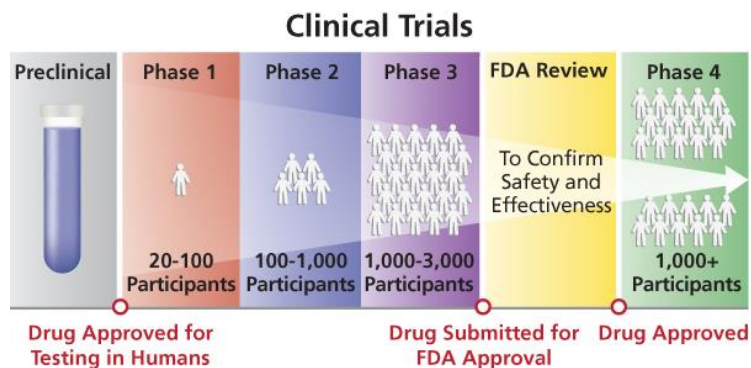Strength in optimism. Hope in progress.

Quality of care

Medications and Physical therapy
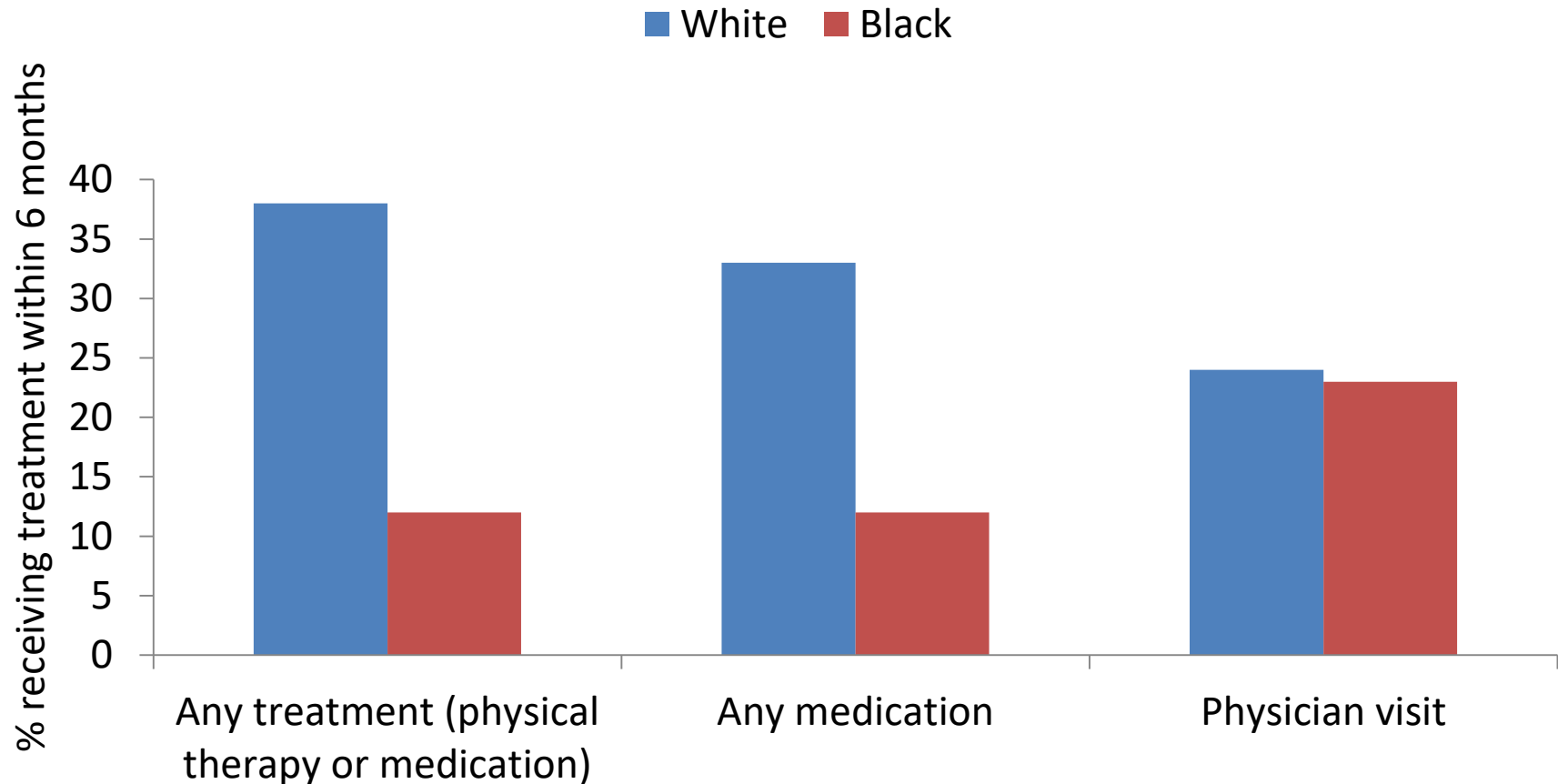

Deep brain stimulation surgery

Enrollment in research

DISPARITIES IN QUALITY OF PD CARE

- Reviewed medical records of 309 white and 65 non-white Los Angeles veterans with PD

- Assessed adherence of previously developed 10 quality indicators

- Whites with PD were more likely to receive higher quality care than non-whites:

  - OR 1.15 [95% CI 1.07-1.32]

- This difference in quality was largely due to difference in depression treatment

  - OR 1.33 [95% CI 1.12 – 2.54]

Cheng EM, et al. Parkinsonism Relat Disord. 2008; 14: 8-14.

INITIATION OF TREATMENT AFTER NEW PD DIAGNOSIS AMONG AFRICAN-AMERICANS

Dahodwala N, et al. Ann Neurol. 2009; 66: 142-45.

HAS MEDICARE PART D HELPED REDUCE DISPARITIES IN PD TREATMENT?

- Medicare Part D intended to increased access to anti-Parkinson drugs

Table. Independent predictors of any PD treatment among Medicare beneficiaries

Covariate	Odds ratio	95% CI	*p*-value
African-American race (ref white)	0.80	0.72-0.91	0.003
Partial low-income subsidy (ref full subsidy)	0.61	0.44-0.85	0.003
Co-morbid depression	1.12	1.04-1.20	0.003
Greater co-morbidities (RxHCC score)	0.54	0.50-0.59	<0.001
Sees a neurologist	2.42	2.26-2.60	<0.001

*Model also controls for age, gender, psychosis, dementia, measures of SES and access to neurologist

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Dahodwala N, et al. Mov Disord Clinic Pract. 2017; 4(3) 335-41.

SURGERY FOR PARKINSON'S DISEASE

- Case series of pallidotomy, thalamotomy and, now, randomized-controlled trials of deep brain stimulation to STN/GPI show efficacy in the treatment of PD

- A review of hospital discharges using the National Inpatient Sample showed that of the 1761 patients that received surgery for PD:
  - **86% (1283) were white**
  - 0.6% (9) were African-American
  - **8.4% (125) were Hispanic**
  - **2.5% (37) were Asian/Pacific Islander**

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Deuschl, et al. NEJM. 2006; 355: 896-908;
Eskandar EM, et al. J Neurosurg. 2003; 99: 863-71.

CLINICAL TRIAL ENROLLMENT

- NIH mandate to include women and minorities in clinical research since 1993

- A review of 32 published clinical trials in PD showed that only 9 reported racial/ethnic composition

- The total number of African-Americans enrolled in these 9 studies was 65 which was 0.9% of the total subjects (7481)

Schneider MG, et al. Parkinsonism Relat Disord 2009; 15: 258-62.

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African-Americans with PD have:

- Lower likelihood of seeing a neurologist and, therefore, are
  - **More likely to be placed in long term care/ skilled nursing facility**
  - **More likely to have a hip fracture**

- Higher mortality

Willis AW. Neurology 2011; 77:851-857;
Willis AW, et al. Arch Neurol. 2012; 69: 601-7;.

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HEALTH DISPARITIES RESEARCH AGENDA

Detecting

Compared to whites, blacks have:
1. Lower rates of PD diagnosis
2. Delayed diagnosis and treatment
3. Less likely to receive high quality care, medications or surgery
4. Lower participation in research

Understanding

Patient
- Health/ PD literacy

Provider/Clinical Encounter
- Uncertainty in diagnosis and treatment
- Trust
- Language
- Bias

Health system
- Access to neurologists

Health

Reducing

- Community education programs
- Media campaigns
- Physician CME / grand rounds
- Practice guidelines
- NIH mandate to increase minority enrollment in research
- Tele-health

1. Still need better understanding of observed racial/ethnic differences in PD diagnosis/ risk
2. Improved access to care and treatment of vulnerable groups already diagnosed with PD
3. Increased enrollment of under-represented groups in PD research
4. Community and patient education programs and campaigns to increase literacy
   - General health
   - PD-specific
   - Computer/technology

HEALTH POLICY

Action

1. Pay for value
   - **Incentives for improved outcomes**
   - **Integrate social and medical services**
2. Empower people
   - **Increase health literacy**
   - **Tele-health**
   - **Personalize care to context**
3. Activate communities
   - **Invest in local public health initiatives**
   - **Community-based health strategies**
4. Connect care

Infrastructure

1. Measure what matters most
2. Modernize skills
   - **Cultural competency training**
3. Accelerate real-world evidence
4. Advance science
   - **Patient-oriented research**

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Dzau V, et al. JAMA. 2017; 317: 1461-70.

THANK YOU

QUESTIONS?