Lessons from George Floyd:

Racial Inequalities in the Treatment of Parkinson's Disease

Presented by
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Disclosures

No relevant conflicts of interest.

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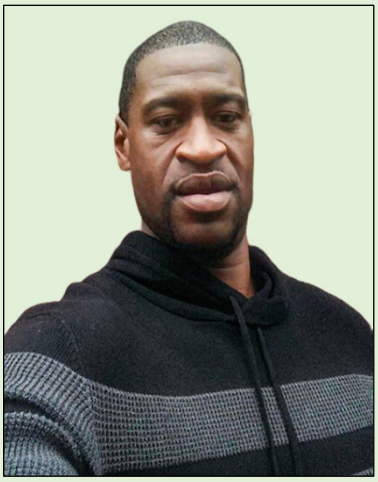
Ahmaud Arbery

Breonna Taylor



George Floyd

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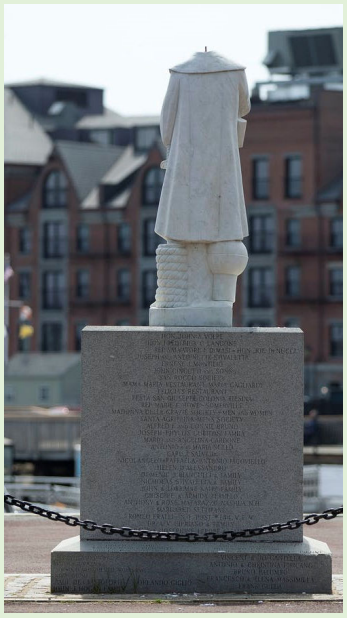

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Uncle Ben's
ORIGINAL
L'ORÉAL
PARIS
Aunt Jemima
The Original
Pancake & Waffle Mix
Farmer Owned
LAND O LAKES
BUTTER SALTED
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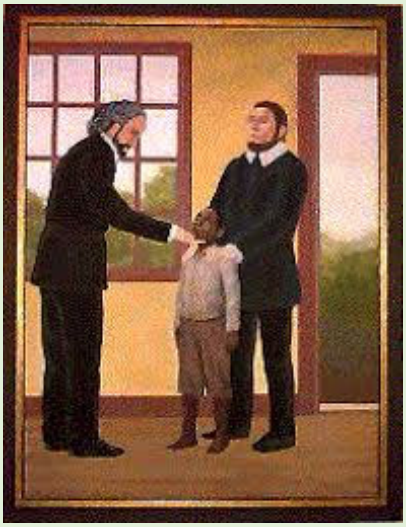
8

Canada



Olivier Le Jeune

- First recorded African slave purchased in Quebec
- Brought to the outpost of Quebec in New France by the English
- Was a young boy from Madagascar, believed to have been approximately 7 years of age
- Was sold to British commander David Kirke or one of his brothers

Williams D. The Canadian Encyclopedia. 2020.

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South Africa

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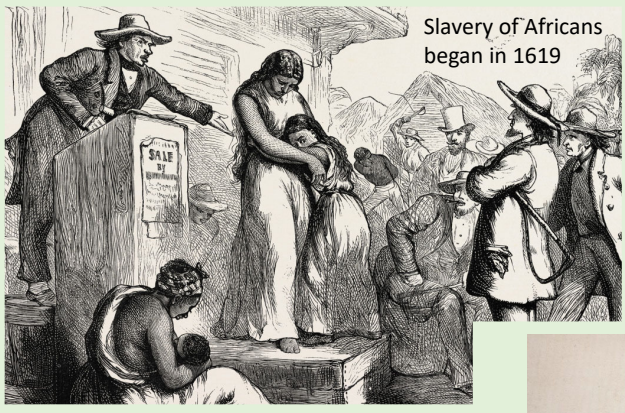

Slavery of Africans began in 1619

United States of America

Tulsa's Black Wall Street Burned in 1921

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Tuskegee Syphilis Study (1932 – 1972) – Taking a blood sample

Henrietta Lacks – Cervical cancer cells taken in 1951

12

12

Outline of Presentation

- Current state of racial disparity within Parkinson's disease
- Disparities in medical management
- Disparities in deep brain stimulation (DBS) treatment
- Barriers to change
- Next steps to mitigate racial inequalities

13

13

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14

14

Current State: Parkinson's Disease (PD)

- Second most common neurodegenerative disorder in the U.S. [1]
- Age-adjusted prevalence of PD more than two-fold lower in Blacks compared to Whites [2]
- Black individuals with PD have a higher risk of death from all causes compared to White individuals after adjusting for age, sex, comorbidity index, socioeconomic status, and treating physician specialty [3]
- Young (ages 40-65 years) African American Medicaid patients with PD diagnosed at half the rate of their White counterparts after adjusting for age, sex, location of care, health care use, and reason for Medicaid eligibility [4]

1. Kowal SL, et al. Mov Disord. 2013; 28(3): 311-318.
2. Willis AW, et al. Neuroepidemiology. 2010; 34(3): 143-151.
3. Willis AW, et al. Archives of Neurology. 2012; 69(5): 601.
4. Dahodwala N, et al. Movement Disorders. 2009; 24(8): 1200-1205.

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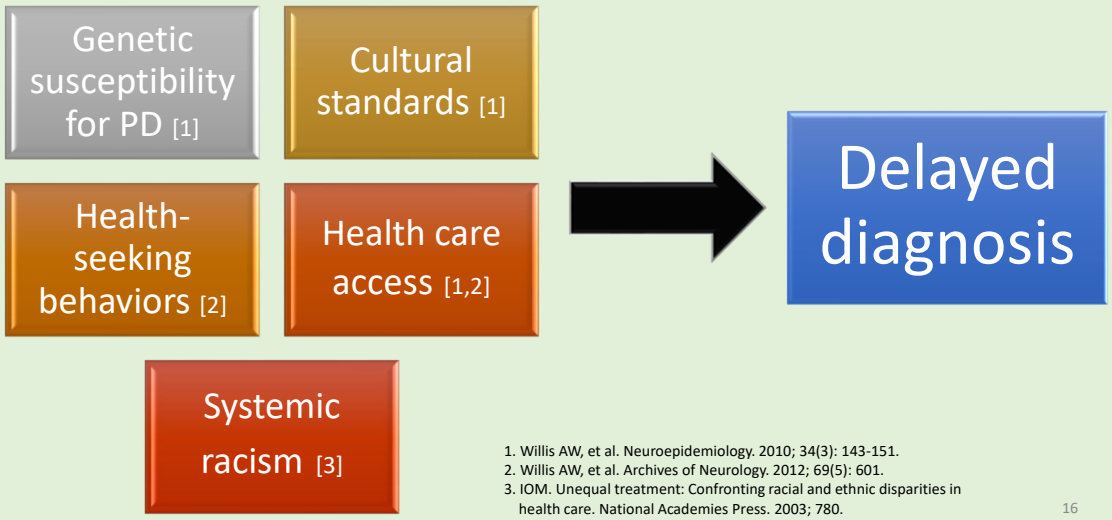
Current State (cont.)

- Possible explanations for racial disparity:



1. Willis AW, et al. Neuroepidemiology. 2010; 34(3): 143-151.
2. Willis AW, et al. Archives of Neurology. 2012; 69(5): 601.
3. IOM. Unequal treatment: Confronting racial and ethnic disparities in health care. National Academies Press. 2003; 780.

16

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17

17

Disparities in Medical Management

- Mainstay medical treatment for PD motor symptoms is carbidopa/levodopa [1]
- However, data regarding medical management of PD by race/ethnicity are limited
- Retrospective cohort study among U.S. veteran patients with PD [2]
  - ❖ If the veteran patient used a dopamine agonist (e.g., bromocriptine, pergolide, pramipexole, ropinirole) as monotherapy for motor symptoms of PD, a statistically lower percentage of non-White veteran patients were titrated to a therapeutic range
  - ❖ Non-White veteran patients had a significantly lower probability of receiving initial treatment or follow-up of treatment for depression (even after adjusting for age, level of comorbidity, duration of PD diagnosis, receipt of non-VA care, annual frequency of visits, and specialty involvement)

1. Stoker TB, et al. Frontiers in neuroscience. 2018; 12: 693.
2. Cheng EM, et al. Parkinsonism Relat Disord. 2008; 14(1): 8-14.

18

18

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19

19

Disparities in DBS Treatment

- Procedural interventions are known to be more definitive treatment options for motor symptoms [1]
- For example, DBS has been an efficacious treatment for more than 20 years [2-4]
- Data for DBS for PD by race/ethnicity: Willis et al., 2014 [5]
  - ❖ Investigation of more than 657,000 Medicare beneficiaries with PD from 2007-2009
  - ❖ Black beneficiaries had a significantly lower likelihood of receiving DBS than their White counterparts
  - ❖ For every one Black patient who received DBS, five White patients received DBS

1. Willis AW, et al. Neurology. 2014; 82(2): 163-171.
2. Williams A, et al. The Lancet Neurology. 2010; 9(6): 581-591.
3. Ho AL, et al. J Neurol Neurosurg Psychiatry. 2018; 89(7): 687-691.
4. Weaver FM. JAMA. 2009; 301(1): 63-73.
5. Willis AW, et al. Neurology. 2014; 82(2): 163-171.

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Disparities in DBS Treatment (cont.)

- Data for DBS for PD by race/ethnicity: Chan et al., 2014 [1]
  - ❖ Investigation of more than 2 million PD discharges from nonfederal U.S. hospitals from 2002-2009
  - ❖ African Americans were nearly 8 times less likely to undergo DBS surgery compared with White patients (after controlling for patient- and hospital-related factors)
- Data for DBS for PD by race/ethnicity: Eskandar et al., 2003 [2]
  - ❖ Investigation of 71 nonfederal U.S. hospitals from 1996-2000, adjusted for year of surgery
  - ❖ 85.9% of patients who underwent DBS surgery for PD were White
  - ❖ 0.6% of patients who underwent DBS surgery for PD were African American
  - ❖ Factors that predicted placement of DBS devices: younger age, White race, private insurance, residence in higher-income areas, hospital teaching status, and smaller annual hospital caseload

1. Chan AK, et al. JAMA Neurology. 2014; 71(3): 291-299.
2. Eskandar EN, et al. J Neurosurg. 2003; 99(5): 863-871.

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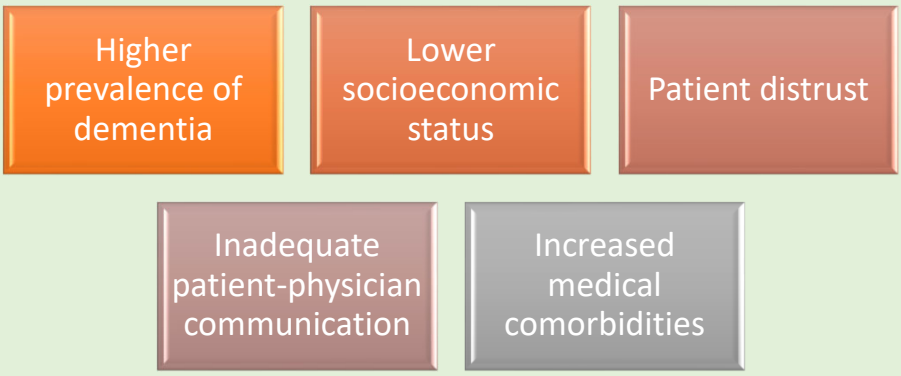
Disparities in DBS Treatment (cont.)

- Possible reasons for lower utilization of DBS among Black PD patients:



Willis AW, et al. Neurology. 2014; 82(2): 163-171.

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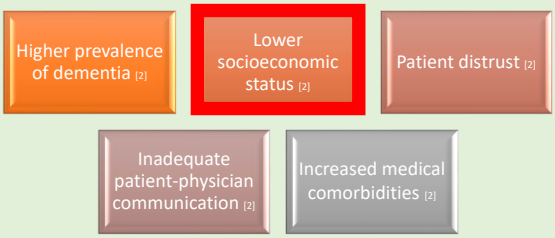
Disparities in DBS Treatment (cont.)

- Possible reasons for lower utilization of DBS among Black PD patients (cont.):
  - ❖ Statistically significant predictor of Black PD patients not receiving DBS was Medicaid use [1]
    - ➢ Chan et al., 2014 (more than 2 million PD discharges from nonfederal U.S. hospitals from 2002-2009)
    - ➢ White patients with PD who used Medicaid received significantly more DBS surgeries than Black patients with PD who *did not* use Medicaid



1. Chan AK, et al. JAMA Neurology. 2014; 71(3): 291-299.
2. Willis AW, et al. Neurology. 2014; 82(2): 163-171.

23

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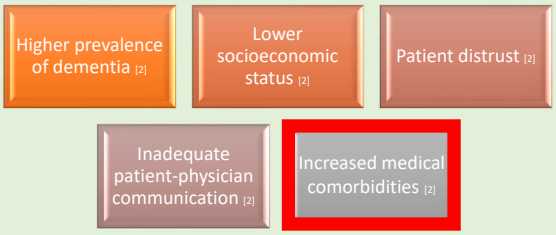
Disparities in DBS Treatment (cont.)

- Possible reasons for lower utilization of DBS among Black PD patients (cont.):
  - ❖ Statistically significant predictor of DBS nonuse was "African American race" [1]
    - ➢ Chan et al., 2014 (more than 2 million PD discharges from nonfederal U.S. hospitals from 2002-2009)
    - ➢ "African American race" still predicted decreased use of DBS among PD patients even after adjusting for comorbidity score (which was indeed higher among Blacks)



1. Chan AK, et al. JAMA Neurology. 2014; 71(3): 291-299.
2. Willis AW, et al. Neurology. 2014; 82(2): 163-171.

24

24

Disparities in DBS Treatment (cont.)

- Possible reasons for lower utilization of DBS among Black PD patients (cont.):
  - ❖ Black PD patients have been shown to still undergo disproportionately fewer DBS procedures despite receiving care at urban teaching hospitals which had a higher than average density of neurologists and neurosurgeons
    - ➢ Chan et al., 2014 (more than 2 million PD discharges from nonfederal U.S. hospitals from 2002-2009)

Chan AK, et al. JAMA Neurology. 2014; 71(3): 291-299.

25

25

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26

26

Barriers to Change

- Various patient-level, provider-level, and system-level factors

- Two main barriers:
  - ❖ Scarcity of race-level data
  - ❖ Minority patients have diminished trust in the health care system

27

27

Barriers to Change (cont.)

- Scarcity of race-level data:
  - ❖ One reason is due to the low number of minorities enrolled in clinical trials
  - ❖ 32 PD clinical trials conducted in the U.S. over a 23-year period
  - ❖ Only 9 of those clinical trials reported detailed racial/ethnic composition of trial participants
  - ❖ Only 1.7% of study participants in those 9 studies were African American

Schneider MG, et al. Parkinsonism & Related Disorders. 2009; 15(4): 258-262.

28

28

Barriers to Change (cont.)

- Minority patients have diminished trust in the health care system:
  - ❖ Stems from past and ongoing patterns of discrimination
  - ❖ "Past and ongoing patterns of discrimination have […] resulted in decreased trust in the health care system in general among minority patients. Minorities are more likely to express concerns about exploitation, dishonesty regarding risks of experimental treatment, and motivations of researchers."

Murthy VH, et al. JAMA. 2004; 291(22): 2720-2726.

29

29

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30

30

Next Steps

- Disparities in treatment demonstrate the continued need for tangible actions
- Issue of health disparities not new [1]
- U.S. Health & Human Services *Healthy People 2020* goal:
  - "To achieve health equity, eliminate disparities, and improve the health of all groups" [2]

1. IOM. Unequal treatment: Confronting racial and ethnic disparities in health care. National Academies Press. 2003; 780.
2. ODPHP, HHS. Healthy People 2020: Disparities. U.S. Dept. of Health & Human Services (HHS), Office of Disease Prevention and Health Promotion (ODPHP). 2014 [updated June 23, 2020].

31

Next Steps (cont.)

- We suggest 3 main strategies as part of the larger process for reconciling these racial inequalities:

1. Implementation of **culture-centered care** in all physician practices
2. Inclusion of **minorities in NIH-funded clinical research/clinical trials**
3. **Incentives**

32

Next Steps – 1. Culture-Centered Care

- Wide variety of trained language interpreters (free of charge)
  - ❖ English, French, Creole, Pidgin English, Portuguese, and Swahili
  - ❖ Language barriers can adversely affect quality of care [1]
- Availability of faith-based clergy
  - ❖ E.g., pastors, bishops, priests
  - ❖ Pray with patient via telephone as he/she waits to be seen by his/her physician for routine care
  - ❖ Religion continues to be a foundational component in Black communities; therefore, health care outcomes may be improved by incorporating faith-based resources [2]

1. Hasnain-Wynia R, Baker DW. Health services research. 2006; 41(4 Pt 1): 1501-1518.
2. Baruth M, et al. Family & Community Health. 2013; 36(3): 204-214.

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Next Steps – 1. Culture-Centered Care (cont.)

- Inclusion of either the main family unit or designated decision-maker in the patient's consultation session
  - ❖ May need to use remote communication via phone or video due to time differences and geographic limitations
- Nutritional counseling
  - ❖ Include foods that are staples of the patient's culture

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Next Steps – 2. Inclusion of Minorities in NIH-Funded Clinical Research/Clinical Trials

- Current federal guidelines mandate inclusion of minorities in NIH-funded clinical research [1]
- Continuing these federal guidelines leads to [1]:
  - ❖ Improved access for Black patients to potentially effective therapies
  - ❖ Ability to determine whether the intervention or therapy under study affects minority groups and their subpopulations differently
- Because of the underlying mistrust that Black communities have toward the health care system, clinical trials must be conducted using transparent, ethical, and sound methodologies

1. NIH. NIH Guide. 1994; 23(11).

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Next Steps – 2. Inclusion of Minorities in NIH-Funded Clinical Research/Clinical Trials (cont.)

- Suggested role of regulatory agencies (e.g., U.S. FDA)
  - ❖ Should not render drug approval if clinical research does not incorporate adequate representation from minority groups
  - ❖ Composition of study minority/ethnic groups should mirror the prevalence rates of ethnic groups for which the drug is intended
  - ❖ This requirement would also be mandatory when a drug's approval process is expedited

36

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Next Steps – 3. Incentives

- Incentives should be given to both manufacturers of interventional medical devices and medical providers whose patient/client racial distribution mirrors that of their general populations

- MassHealth [1,2]
  - ❖ State of Massachusetts
  - ❖ Incorporated a pay-for-performance plan within its Medicaid program in 2007
  - ❖ One goal of this plan was for hospitals to reduce racial/ethnic disparities in designated quality standards and performance benchmarks

- CalHealthCares [3]
  - ❖ Loan repayment program for California physicians and dentists
  - ❖ Pays up to $300,000 in outstanding educational debt per accepted applicant in exchange for the recipient's commitment to maintain at least a 30% caseload of Medi-Cal beneficiaries

1. Weinick RM, et al. Massachusetts Medicaid Policy Institute; Metrowest Community Health Care Foundation. 2007.
2. Angeles J, Somers SA. Center for Health Care Strategies, Inc. 2007.
3. CMA. California Medical Association. 2019.

37

Conclusions

- Health disparities have been a by-product of systemic racism and social injustice for centuries

- Critical time in our world's history

- Create a new paradigm

- All patients with movement disorders have the same likelihood of receiving life-enhancing treatments, regardless of the patient's race/ethnicity

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Thank You

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