Life Expectancy for Individuals with Alzheimer's Disease or Related Disorders:

Evidence of a Black / White Mortality Crossover

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South Carolina Alzheimer's Disease Registry

South Carolina Demographics

- *South Carolina has about 4 million residents.*

- *About 858,000 were age 55 or over in 2000, with about 50,000 of these age 85 or older.*

- *Almost all older residents are either European American or African American (29.5%).*

- *They have less education than the average older American.*

- *About 40% reside in rural areas.*

South Carolina Alzheimer's Disease Registry

Studies Alzheimer's Disease and related disorders.

Since 1988.

One of only two population-based state AD registries in the United States.

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ADRDs

Alzheimer's disease

Vascular dementia
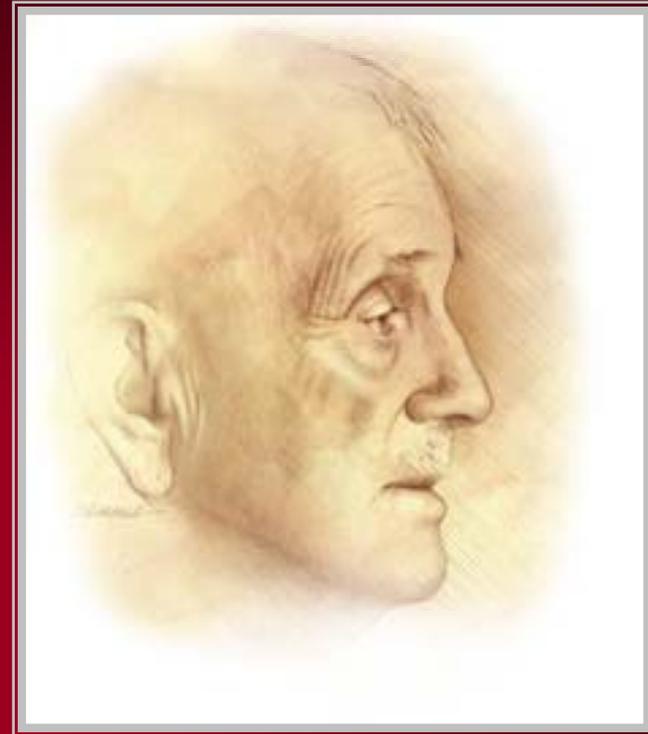
Mixed dementia
(25%-60%) (?)

Alcohol-related dementia

Drug-induced dementia

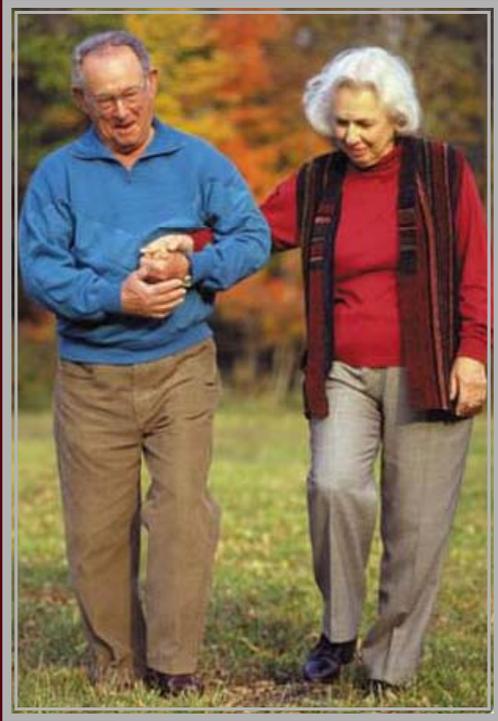Dementia associated with Parkinson's disease

Dementia associated with Huntington's disease

Dementia associated with H.I.V.

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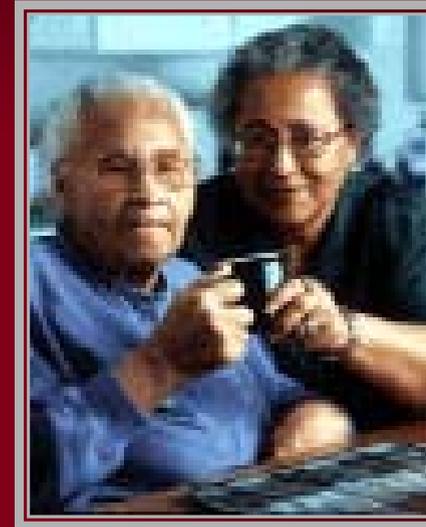SOUTH CAROLINA

The Impact of AD in the U.S.

AD is a major public health problem

- About 4.3 million Americans have AD.

- Expect 13.2 million by 2050.

- Hospitalization costs alone are 63% of Medicare costs.

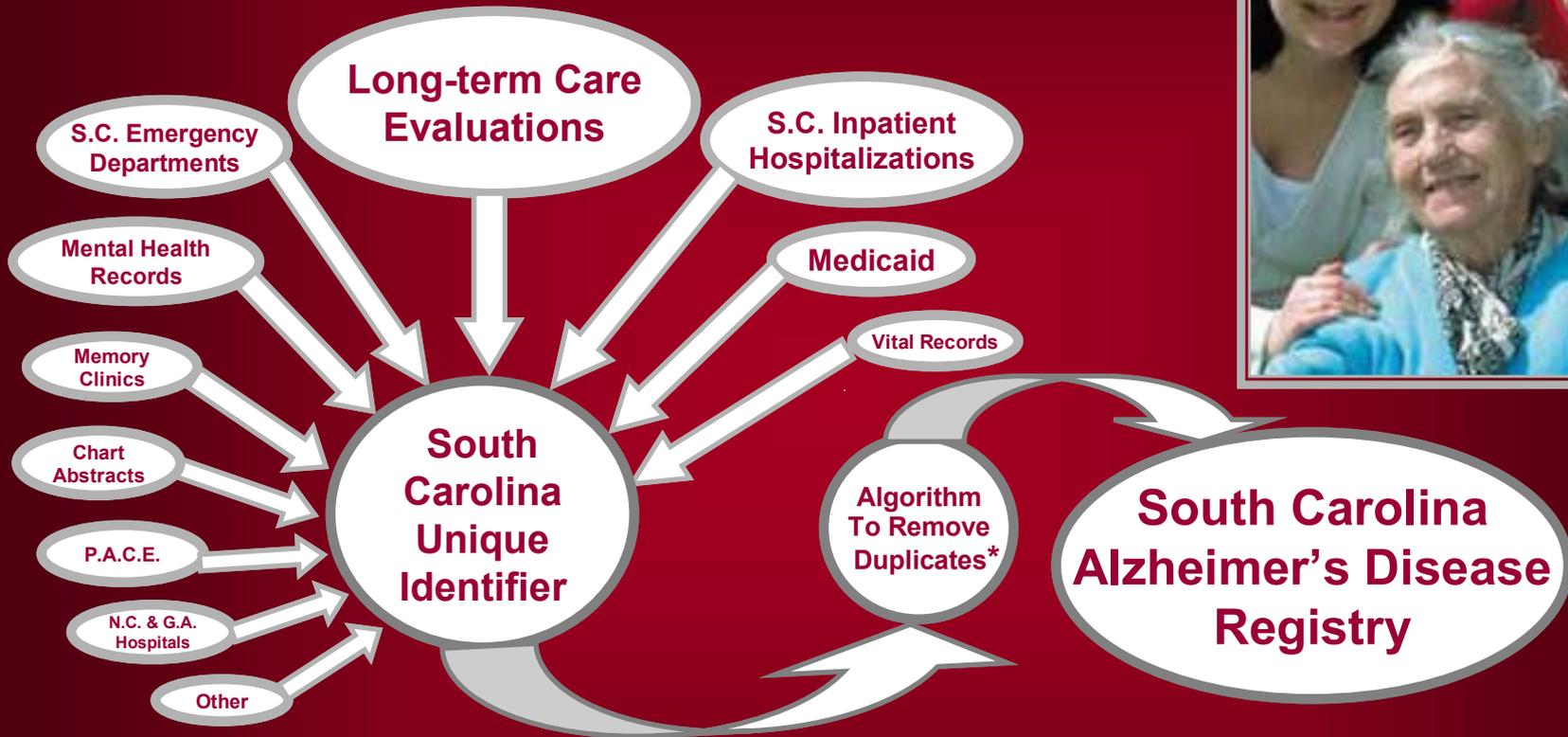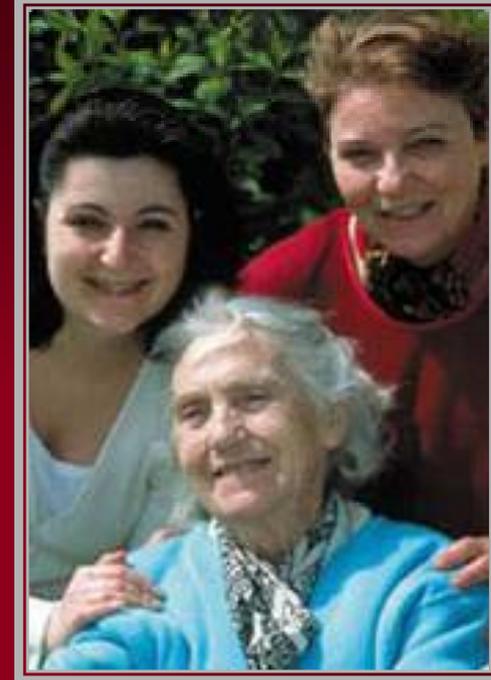- The national cost of caring for people with AD is about $100 billion every year.

Risk Factors for ADRD

- Advancing Age

- Family History

- Obesity

- Vascular disease & Hypertension

- Diabetes

- Having low educational attainment or quality

- Lack of engagement in social, intellectual, and/or physical activities

- Diets high in fat (especially for ApoE4 individuals), low in fish and/or fruits/vegetables, or low in B vitamins and folates (homocysteine risk)

Data Sources

- S.C. Emergency Departments
- Long-term Care Evaluations
- S.C. Inpatient Hospitalizations
- Mental Health Records
- Medicaid
- Memory Clinics
- Vital Records
- Chart Abstracts
- P.A.C.E.
- N.C. & G.A. Hospitals
- Other

South Carolina Unique Identifier

Algorithm To Remove Duplicates*

South Carolina Alzheimer's Disease Registry

Duplicates occur because individuals sometimes use more than one name, social security number, or other identifying information when using health or social services.

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"True Prevalence?"

The SC Alzheimer's Disease Registry

- Large, population-based

- High "power" for discerning subgroup differences

- Diagnoses by physicians of all specialties (accuracy issue?)

- Will not include MCI

- Will not include cases diagnosed in MD office visits, if not linked to our data sources

- Especially useful for examining prevalence of disease in its most costly stages

The Rest of the ADRD Epid. World

- Clinical studies, smaller samples

- Low "power" for discerning subgroup differences

- Diagnoses by specialists

- Sometimes include "Mild Cognitive Impairment" (approx. 50%) or "Questionable AD"

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Registry Cases by Dementia Type and Location
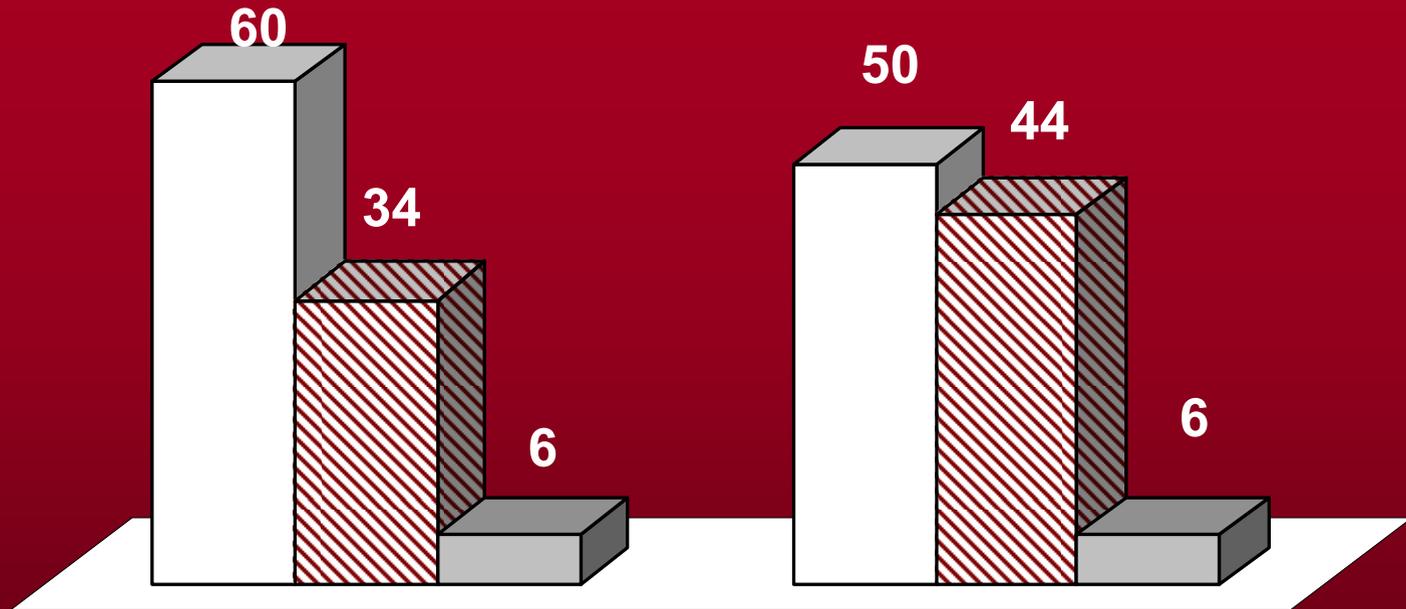## South Carolina Alzheimer's Disease Registry, 2002

Dementia Type	Community N (%)	Nursing Facility N (%)	Unknown N (%)	Total N (%)
Alzheimer's disease	13,803 (60)	10,643 (62)	1,686 (66)	26,132 (61)
Vascular dementia	3,684 (16)	3,306 (19)	185 (7)	7,175 (17)
Other conditions	5,486 (24)	3,292 (19)	673 (27)	9,451 (22)
Total	22,973 (100)	17,241 (100)	2,544 (100)	42,758 (100)

Where do People with ADRD Live?
(Percentages)

Chart showing percentages for African American and White populations:

African American:
- Community: 60
- Nursing Facility: 34
- Unknown: 6

White:
- Community: 50
- Nursing Facility: 44
- Unknown: 6

Legend:
- Community
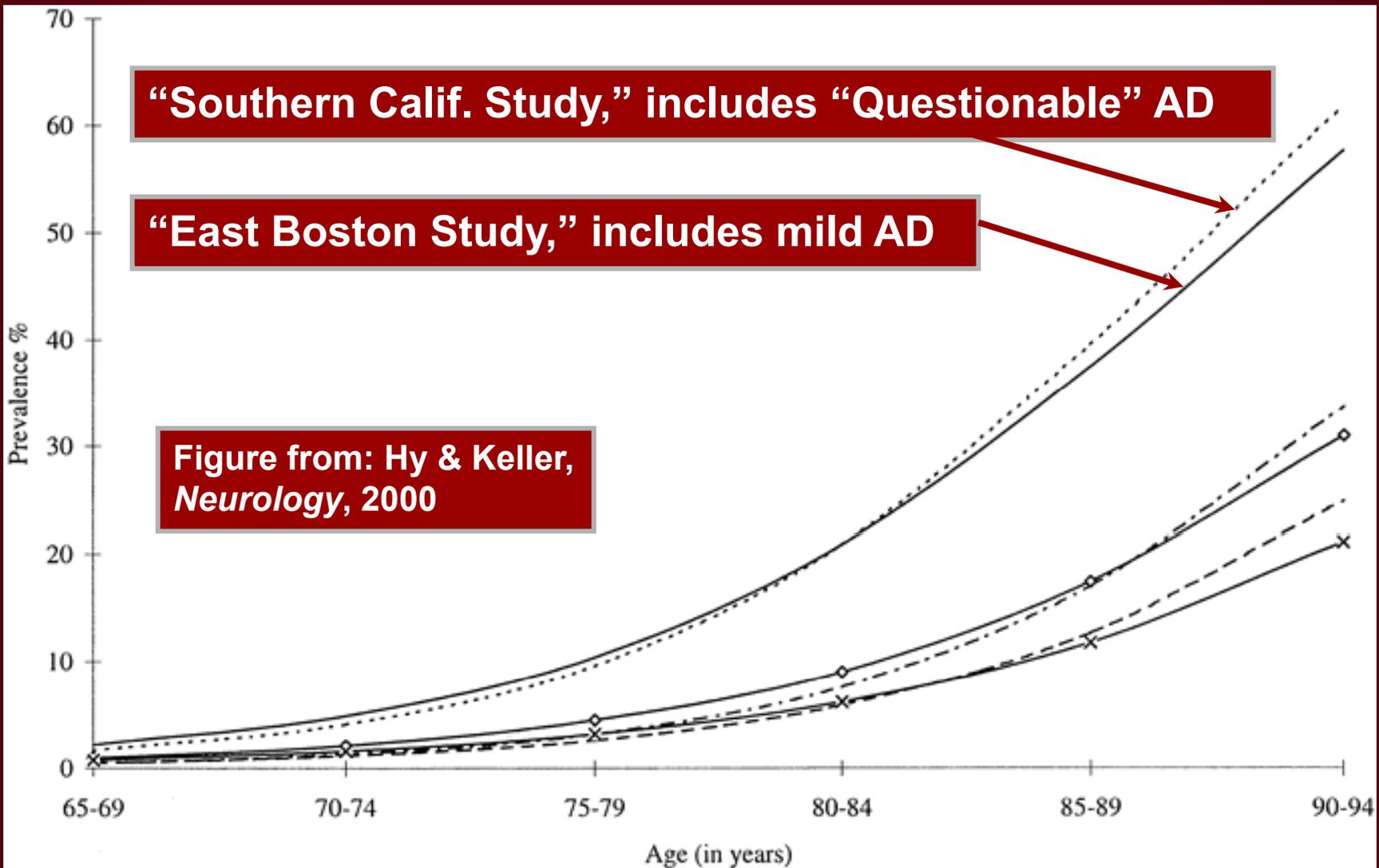- Nursing Facility
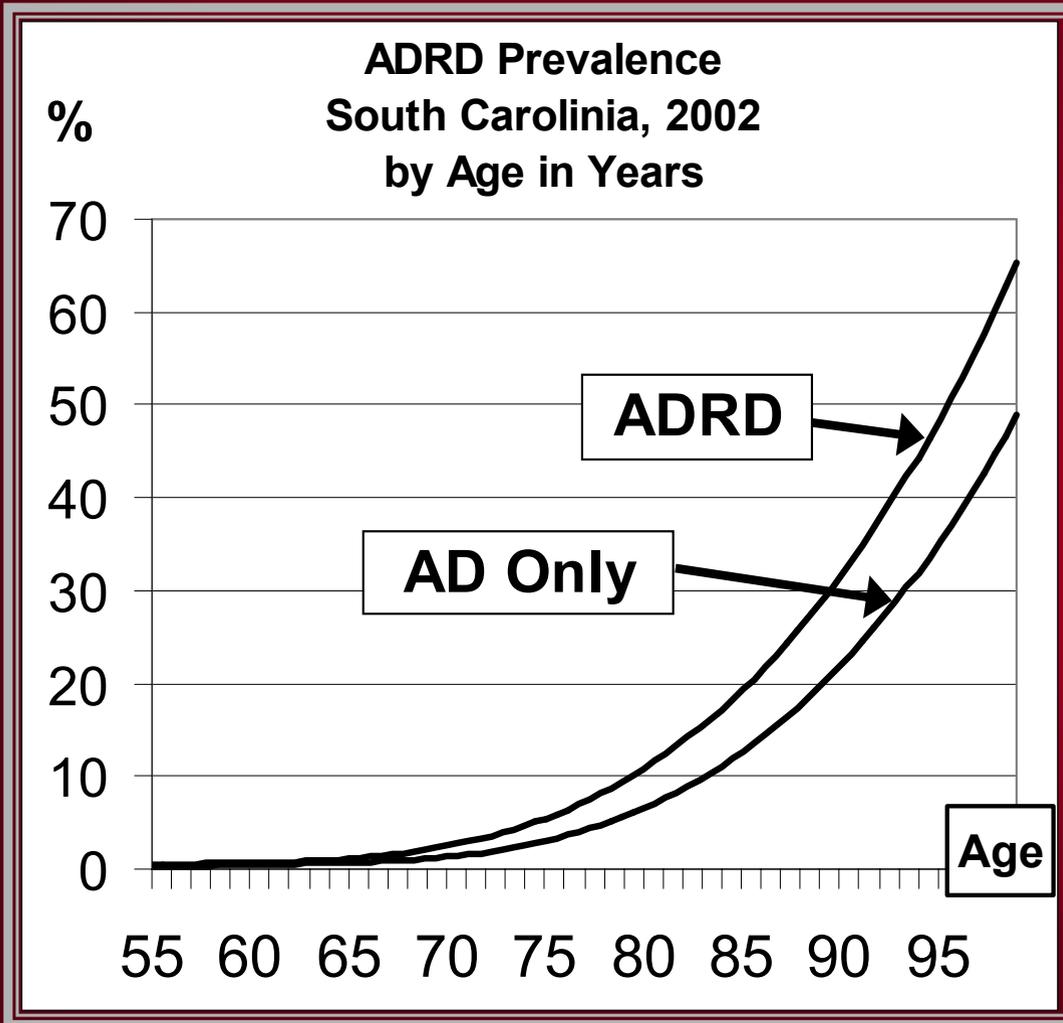- Unknown

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Methods

- Combine U.S. Census with Registry data.

- Estimate prevalence of AD and years lived after diagnosis.

- In total and for groups defined by age, gender, and race.

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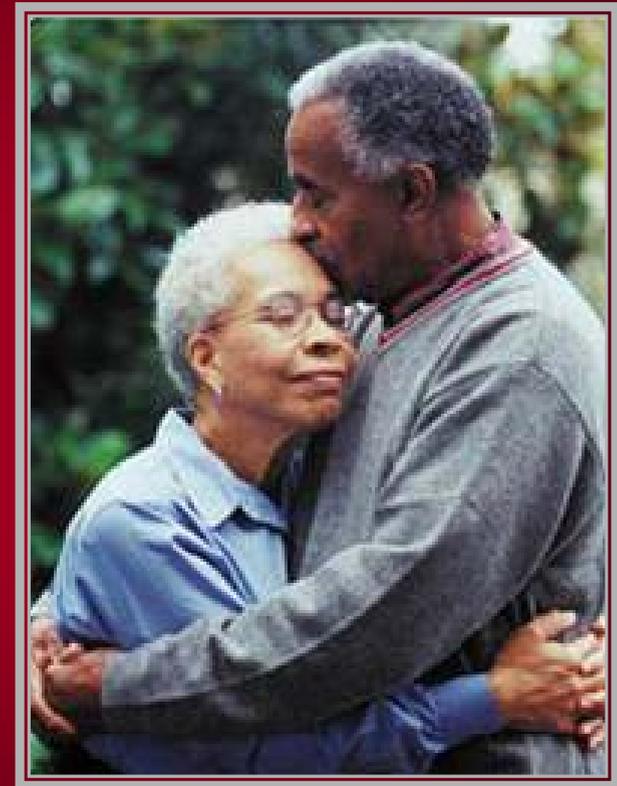
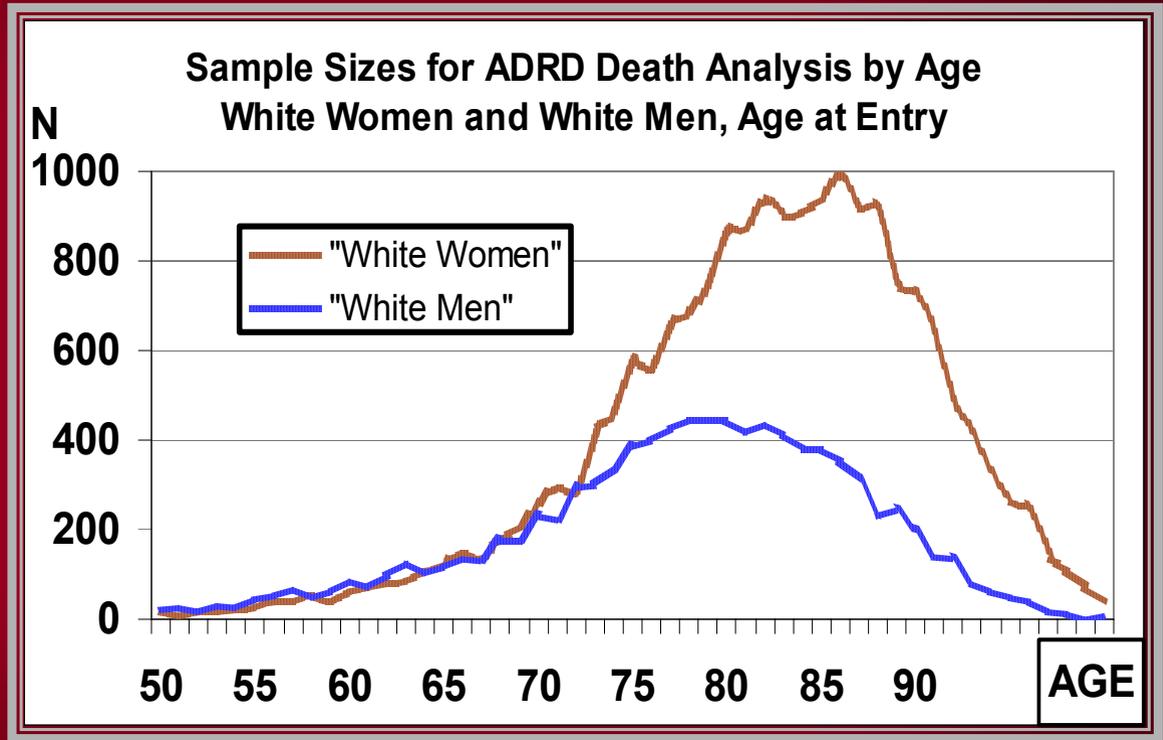# National AD Prevalence

"Southern Calif. Study," includes "Questionable" AD

"East Boston Study," includes mild AD

Figure from: Hy & Keller, *Neurology*, 2000

South Carolina AD Prevalence

ADRD Prevalence
South Carolinia, 2002
by Age in Years

South Carolina ADRD Survival

Sample Sizes for ADRD Death Analysis by Age
White Women and White Men, Age at Entry

- "White Women"
- "White Men"
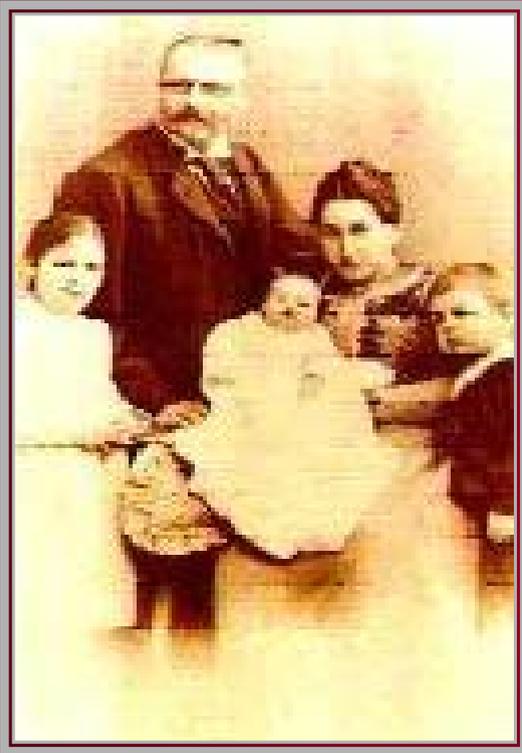
Years from Diagnosis to Death
Alzheimer's Disease -- Men

Years

black
white

$y = 0.015x + 1.4978$
$R^2 = 0.1738$

$y = 0.0146x + 1.4667$
$R^2 = 0.4465$

DX Age

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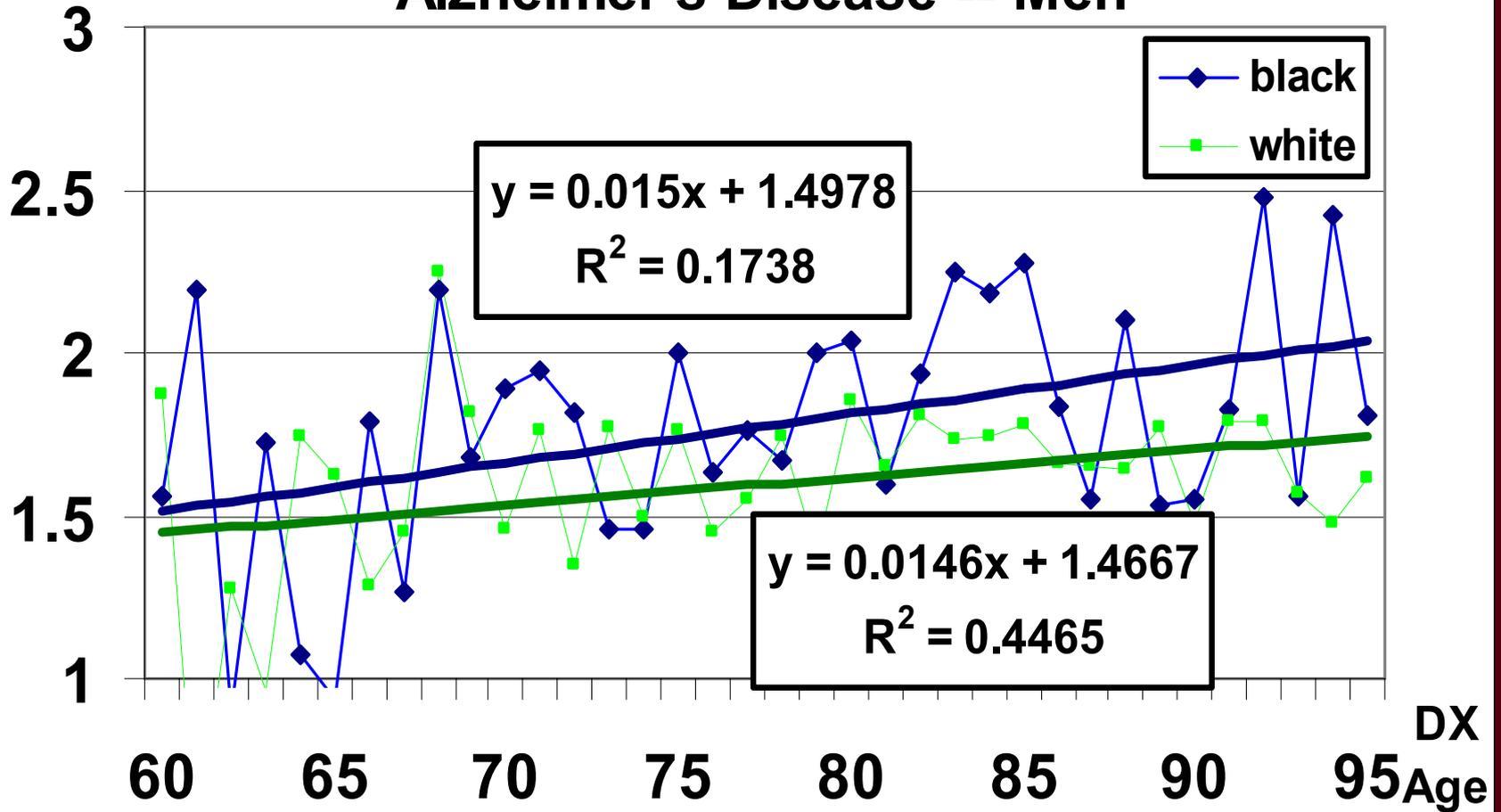
Years from Diagnosis to Death
Alzheimer's Disease -- Women

$y = 0.0117x + 1.8782$
$R^2 = 0.0984$

$y = 0.018x + 1.5424$
$R^2 = 0.3929$

Years

black
white

DX Age

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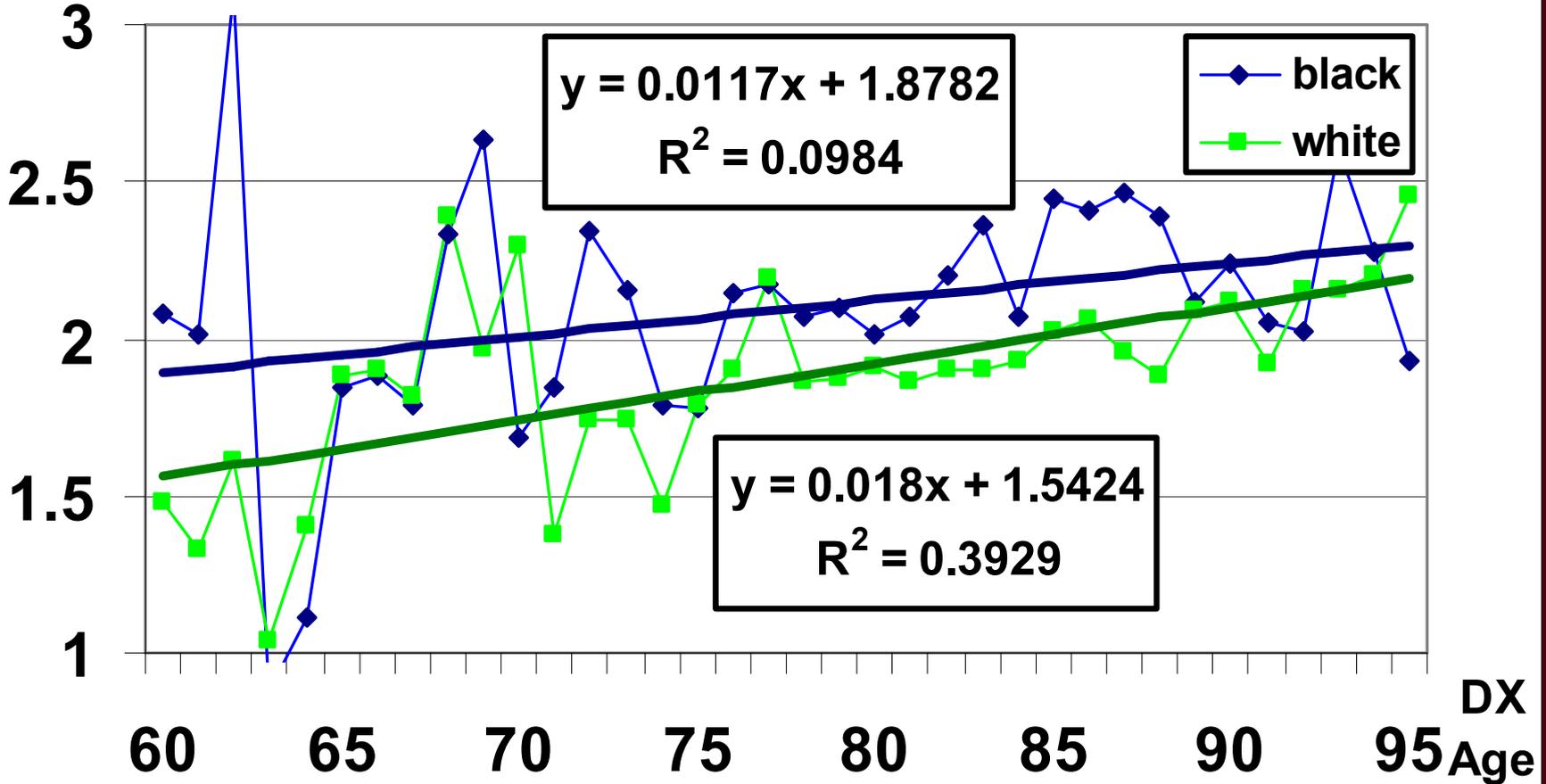
Years from Diagnosis to Death
Vascular Dementia -- Men

Years

White
$y = 0.0146x + 1.4667$
$R^2 = 0.4465$

Black
$y = 0.0098x + 1.6856$
$R^2 = 0.0622$

black
white

DX Age

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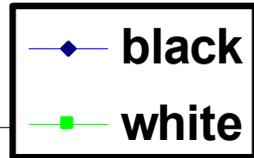
Years from Diagnosis to Death Vascular Dementia -- Women

Years

$y = 0.0107x + 1.9505$
$R^2 = 0.0463$

$y = 0.0146x + 1.4667$
$R^2 = 0.4465$

black
white

DX Age

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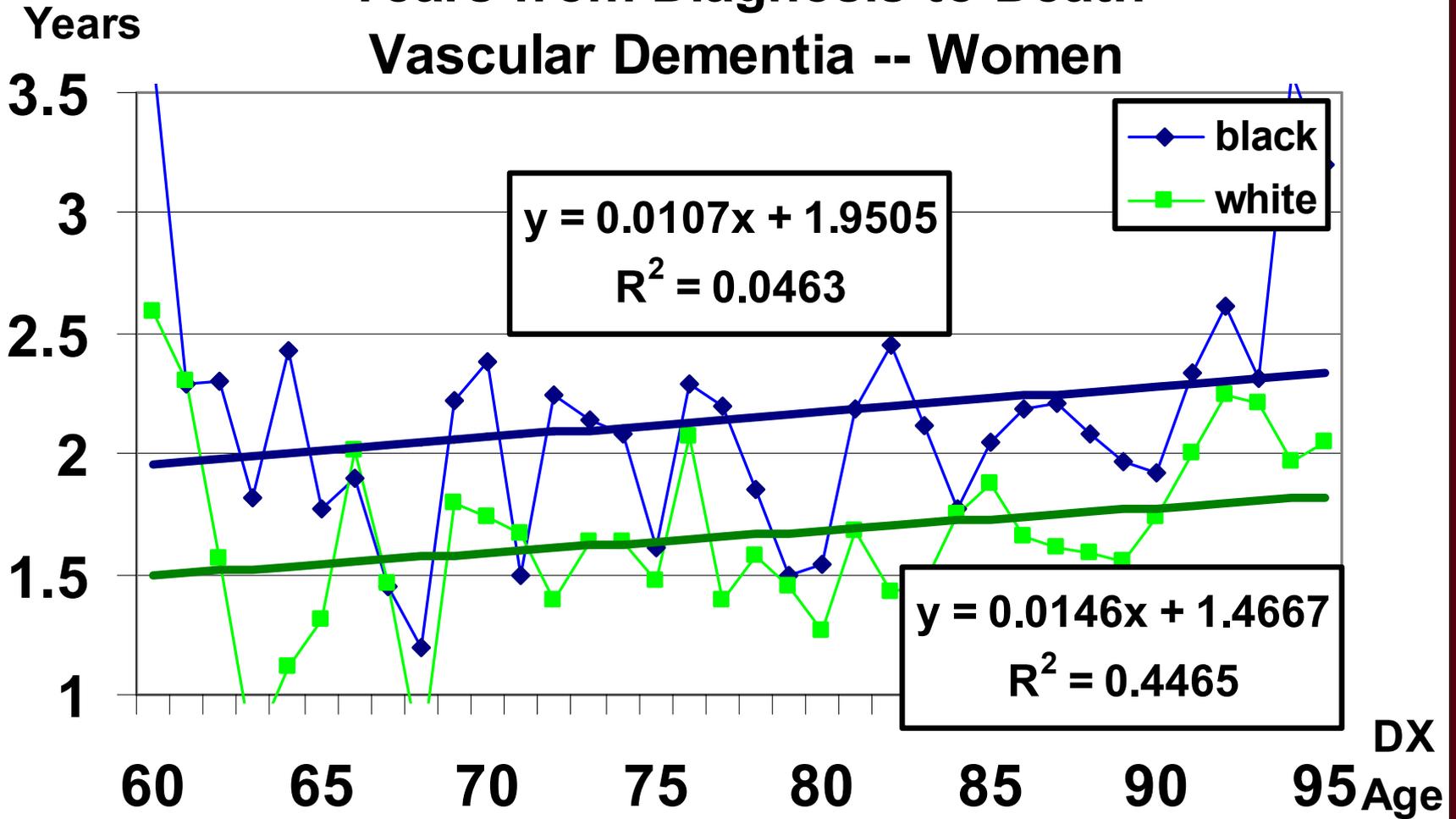
Years from Diagnosis to Death
Dementias with Medical Conditions -- Men

Years

- black
- white

$y = -0.1026x + 4.235$
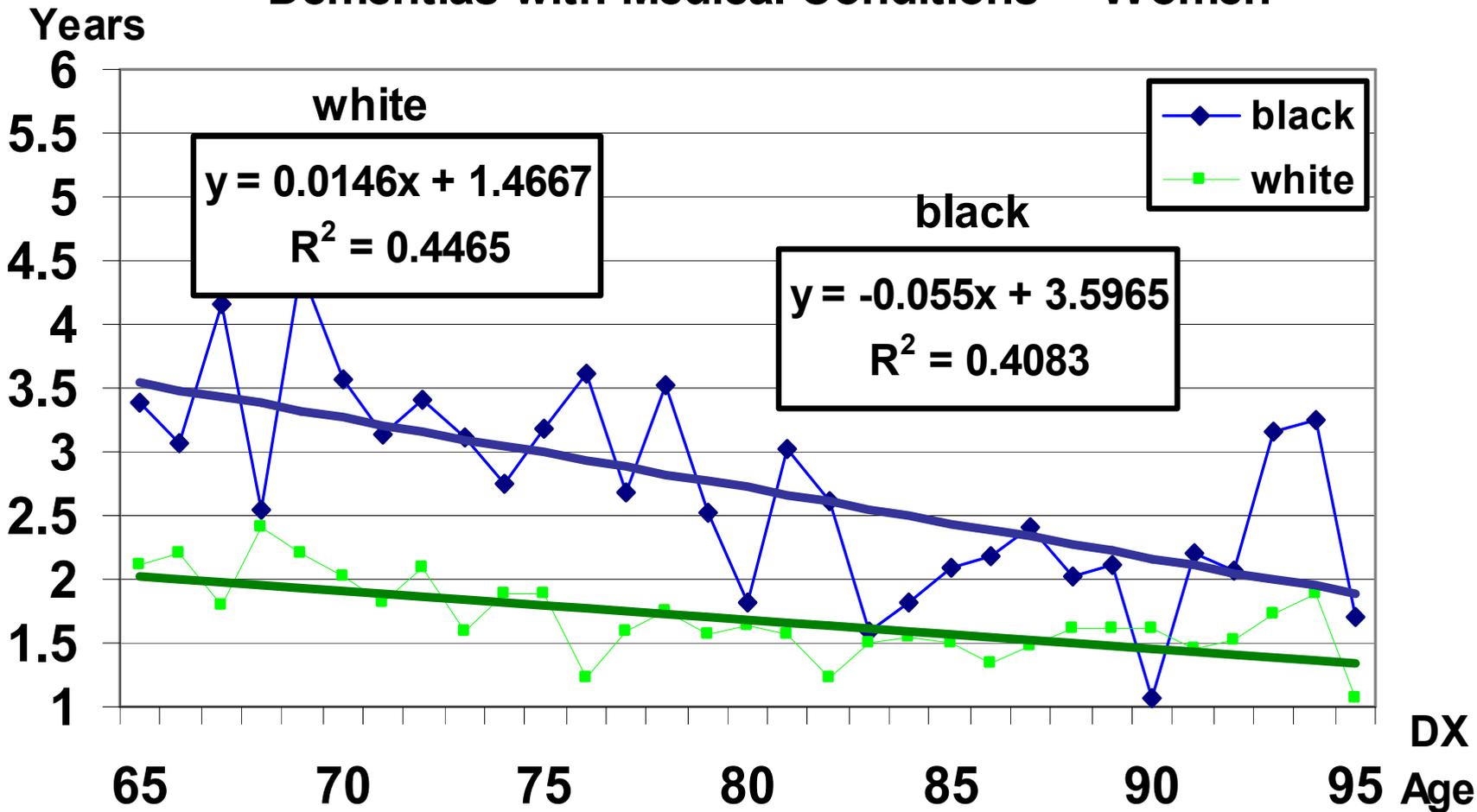$R^2 = 0.4856$

$y = 0.0146x + 1.4667$
$R^2 = 0.4465$

DX Age

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Years from Diagnosis to Death
Dementias with Medical Conditions -- Women

Years

white

$y = 0.0146x + 1.4667$

$R^2 = 0.4465$

black

$y = -0.055x + 3.5965$

$R^2 = 0.4083$

Legend: black, white

DX Age

Implications

- *There is strong evidence that blacks may live longer with dementing illnesses than do whites.*

- *There is some evidence of a black / white mortality crossover among men with vascular dementia.*

- *Years lived with these diseases also differs substantially between blacks and whites; the difference varies notably depending upon age at diagnosis.*

Research Strengths

- Statewide population based registry

- Multiple data sources with a history of validity checks

- Recent data

- Ability to examine prevalence and survival for blacks and other groups

Primary Research Challenges

Accuracy and consistency of physician diagnoses

Bias for group comparisons related to diagnosis patterns?

- Men / Women

- Whites / Blacks

- Younger Old / Older Old

Policy Implications

- *Blacks generally live more years with dementing illnesses than do whites.*

- *This larger number of years lived requires more resources for long term care.*

- *Among those with dementia, blacks are more likely to live in the community.*

- *Caregiving needs associated with dementia may be greater for blacks.*

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Thank You!

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