

The structural and non-medical drivers of Alzheimer's and related dementia in people with HIV: a mixed method

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UNIVERSITY OF
South Carolina

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OUTLINE

- Project aims or research questions
- Guiding framework or conceptual model
- Methods and approach
- Preliminary findings
- Implications of NMDOH and for HC, CE and/or IS research and practice
- Lessons learned and challenges encountered
- Future directions



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PROJECT AIMS

- **Aim 1:** Identify the structural and social drivers of Cognitive Impairment among PWH, using data from All of Us research program between 2018 and 2023
- **Aim 2:** Conduct in-depth qualitative interviews for both healthcare providers and PWH in a partnering HIV community organization, aiming to better understand the lived experiences of individuals managing both HIV and HAND/HAD and gain insights from providers.



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GUIDING FRAMEWORK

EHR+Survey data

- HIV cohort, outcome measure
- Basics: demo information
- Social determinants of health domain
- Healthcare utilization
- Personal medical history
- HIV markers

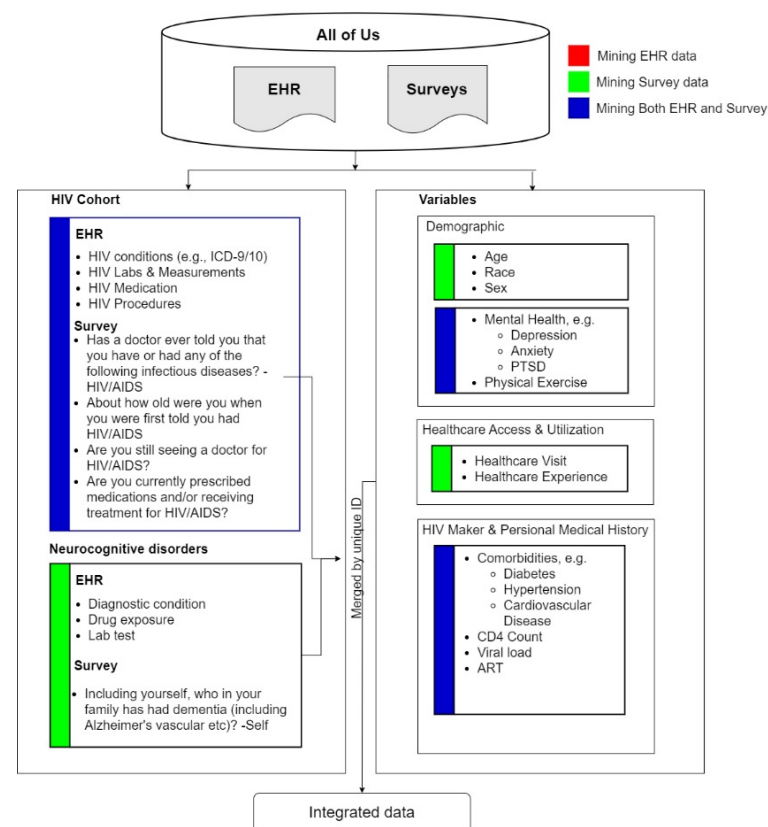


Figure 1 Flowchart for Data Extraction and Integration

Qualitative study-Methods and approach

- **Setting and recruitment:** South Carolina; local AIDS service organization (PALSS) and Immunology center (HIV clinic within a large healthcare system (Prisma health))
- **Participants:**
 - PLWH aged 50+ reporting cognitive decline symptoms such as memory loss
 - HIV Healthcare workers who have job roles with direct, face-to-face contact with PLWH
- **Data collection:** In-depth qualitative interviews; audio-recorded and transcribed verbatim
- **Analysis:** Hybrid inductive-deductive thematic analysis using NVivo

RESEARCH PARTICIPANTS NEEDED!

You are invited to take part in a research study at the University of South Carolina. We want to learn more about memory and thinking changes in people living with HIV and how life experiences—such as access to health care, money, and community support—may affect these changes.



JOIN US

WHO CAN PARTICIPATE

- HIV healthcare workers who worked in HIV services in a clinical capacity
- Have job roles with direct, face-to-face contact with people with HIV (e.g., support workers, caseworkers, counselors, directors, and case managers)

WHAT'S INVOLVED

- One interview
- Takes about 30–45 minutes
- You can choose in-person or virtual

WHAT YOU'LL GET!

- A chance to share your experiences and help improve care for others
- A gift card (\$50) to thank you for your time!

INTERESTED AND HAVE QUESTIONS?

☎ 803-777-8941

✉ xueyyang@mailbox.sc.edu

📍 915 Greene St, Room 534B, Columbia, SC, 29208



Scan here to sign up

RESEARCH PARTICIPANTS NEEDED!

You are invited to volunteer for a research study sponsored by the University of South Carolina. The purpose is to specifically identify the structural and social determinants of HIV-associated neurocognitive disorder among PWH, including health care access and utilization, socioeconomic status, and social environmental factors.



JOIN US

WHO CAN PARTICIPATE

- Have a confirmed HIV diagnosis
- Aged >50 years old
- Experienced changes in memory, attention, or thinking — such as forgetting things more often, difficulty focusing, or feeling slower when processing information

WHAT'S INVOLVED

- A single interview
- 30–45 minutes
- In person/virtual decided by participant

WHAT YOU'LL GET!

- Your voice and experiences will help shape how future care and support are provided
- Gift card in appreciation of your time!

INTERESTED AND HAVE QUESTIONS?

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RESULTS-STUDY SAMPLE (PLWH)

	Overall (N=20)
Age	
Mean (SD)	60.5 (5.12)
Median [Min, Max]	61.5 [50.0, 70.0]
Sex	
Female	12 (60.0%)
Male	8 (40.0%)
Marital_status	
Divorced	3 (15.0%)
Married	3 (15.0%)
Partnered	1 (5.0%)
Single	12 (60.0%)
Widowed	1 (5.0%)
Race	
Black/African American	16 (80.0%)
White	4 (20.0%)
Education	
College degree	2 (10.0%)
High school/GED	8 (40.0%)
Less than high school	2 (10.0%)
Postgraduate	3 (15.0%)
Some college/associate degree	5 (25.0%)
Employment	
Disabled	7 (35.0%)
Full-time	4 (20.0%)
Part-time	2 (10.0%)
Retired	4 (20.0%)
Unemployed	3 (15.0%)

HIV_duration	
Mean (SD)	26.4 (6.52)
Median [Min, Max]	28.5 [13.0, 37.0]
ART	
Yes	19 (95.0%)
Yes (LAI)	1 (5.0%)
Insurance	
Medicaid	5 (25.0%)
Medicaid & Medicare	2 (10.0%)
Medicare	4 (20.0%)
Other (VA)	1 (5.0%)
Private	6 (30.0%)
Public	2 (10.0%)
Housing	
Homeless	2 (10.0%)
Own home (pay mortgage)	3 (15.0%)
Renting	13 (65.0%)
Staying with others	1 (5.0%)
Temporary/shelter	1 (5.0%)
Transportation	
Other (Bicycle)	1 (5.0%)
Personal car	9 (45.0%)
Public transportation / ride from others	9 (45.0%)
Walk	1 (5.0%)

20 PLWH interviewed



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Shi, et al, unpublished

RESULTS-STUDY SAMPLE (HCP)

7 HCPs interviewed

- All female
- Diverse race, professional roles

	Overall (N=7)
Age	
Mean (SD)	39.1 (8.53)
Median [Min, Max]	39.0 [26.0, 49.0]
Sex	
Female	7 (100%)
Marital status	
Divorced	1 (14.3%)
Married	3 (42.9%)
Single	3 (42.9%)
Race	
Black/African American	5 (71.4%)
White	2 (28.6%)
Education	
College	3 (42.9%)
Postgraduate	4 (57.1%)
HIV work experience	
>5 years	3 (42.9%)
1-2 years	2 (28.6%)
3-5 years	2 (28.6%)
Organizations	
Community-based organization	3 (42.9%)
Hospital	4 (57.1%)
Professional role	
Housing case manager	1 (14.3%)
Medical case manager	2 (28.6%)
Nurse manager	1 (14.3%)
Program manager	3 (42.9%)



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PRELIMINARY FINDINGS

Cognitive symptoms and daily impact

- **Common symptoms:** Memory loss, word-finding difficulty, and slowed thinking
- **Functional impact:** Cognitive changes affected communication, routines, appointments, and daily functioning
- **Participant experience:** Concerns were intertwined with aging, HIV, and chronic stressors
- **Emerging need:** Earlier identification and practical supports for day-to-day functioning

Barriers outside the clinic

- **Structural barriers:** Financial strain, housing instability, transportation challenges, and limited information
- **Social isolation:** Limited support and community engagement reduced opportunities for help-seeking
- **Cultural norms:** Strong values of independence and self-reliance delayed asking family or networks for support
- **Stigma:** HIV- and cognitive decline-related stigma shaped disclosure and reduced support

Healthcare system gaps and implications

- **Healthcare system gaps:** Concerns were sometimes dismissed or not fully addressed
- **Access gaps:** Limited access to specialized cognitive services and clear referral pathways



IMPLICATIONS

- **Care implications:** Person-centered HIV care should validate cognitive concerns and connect people to resources
- **Practice implications:** Culturally responsive outreach can address stigma, isolation, and trust
- **Next step:** Integrate cognitive health supports into HIV care for underserved older adults



QUANTITATIVE STUDY:

SDoH Effect on Cognitive Impairment among PWH

- **Data Source:** All of Us (AoU) Version8 Controlled-Tier Database, updated until Dec.2023
- **Design:** Cross-sectional retrospective study
- **Population & Inclusion Criteria:**
 - Confirmed PWH, identified using validated computational phenotyping
 - Age over 18 years old
 - Without cognitive impairment prior to HIV diagnosis
 - Completed SDoH-related surveys
- **Primary Outcome:** Cognitive impairment (Include mild or moderate cognitive impairment, Alzheimer's disease, HIV-associated dementia, and other dementia diagnoses)
- **Main Measurements (Covariates):**
 - Individual-level: basic demographic, HIV indicator (CD4 count, Viral Load)
 - Non-medical drivers: neighborhood cohesion, neighborhood disorder, social support, etc.



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Statistical Analysis

I. Data Preprocessing

- 22 SDoH domain factors constructed from “*Basic Survey*”, “*Social Factors of Health Survey*” and “*Health Care Access and Utilization Survey*”.
- Multiple Imputation (MI) algorithm applied to address data missingness

II. Model Building

- Multiple machine learning classification models developed: LASSO, Random Forest, XGboost, to predict incidence of MCI/Dementia
- Model performance assessed by matrix including AUC, sensitivity, F1, AUPRC

III. Model Interpretation

- Permutation importance rank and SHapley Additive exPlanations (SHAP) are applied to interpretate each factor's contribution and effect on outcome



Results - Demo Descriptive

Variables	Overall PWH (N=2265)	No Cognitive impairment (n=2078)	Cognitive impairment (n=187)	P
Age	55.0 (12.9)	54.8 (13.0)	57.7 (12.0)	0.002
Age Group				
18-44	547 (24.2%)	510 (24.5%)	37 (19.8%)	0.025
45-54	425 (18.8%)	397 (19.1%)	28 (15.0%)	
55-64	778 (34.3%)	714 (34.4%)	64 (34.2%)	
65+	515 (22.7%)	457 (22.0%)	58 (31.0%)	
Sex				
Male	1,782 (78.7%)	1636 (78.7%)	146 (78.1%)	0.908
Female	483 (21.3%)	442 (21.3%)	41 (21.9%)	
Race/Ethnicity				
Non-Hispanic White	1033 (45.6%)	948 (45.6%)	85 (45.5%)	0.037
Non-Hispanic Black	621 (27.4%)	582 (28.0%)	39 (20.9%)	
Asian/Other/Unknown	611 (27.0%)	548 (26.4%)	63 (33.7%)	
Viral Load Level				
Low (< 200 copies/mL)	530 (23.4%)	467 (22.5%)	63 (33.7%)	<0.001
High (≥ 200 copies/mL)	137 (6.0%)	110 (5.3%)	27 (14.4%)	
Unknown	1598 (70.6%)	1501 (72.2%)	97 (51.9%)	
CD4 Count				
High (≥ 500 cells/μL)	560 (24.7%)	487 (23.4%)	73 (39.0%)	<0.001
Low (<500 cells/μL)	232 (10.2%)	186 (9.0%)	46 (24.6%)	
Unknown	1473 (65.0%)	1405 (67.6%)	68 (36.4%)	
APOE Epsilon4				
Carrier	1250 (55.2%)	1144 (55.1%)	106 (56.7%)	0.006
Noncarrier	491 (21.7%)	438 (21.1%)	53 (28.3%)	
Unknown	524 (23.1%)	496 (23.9%)	28 (15.0%)	

Zhang, et al, under review



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Results – SDoH Descriptive

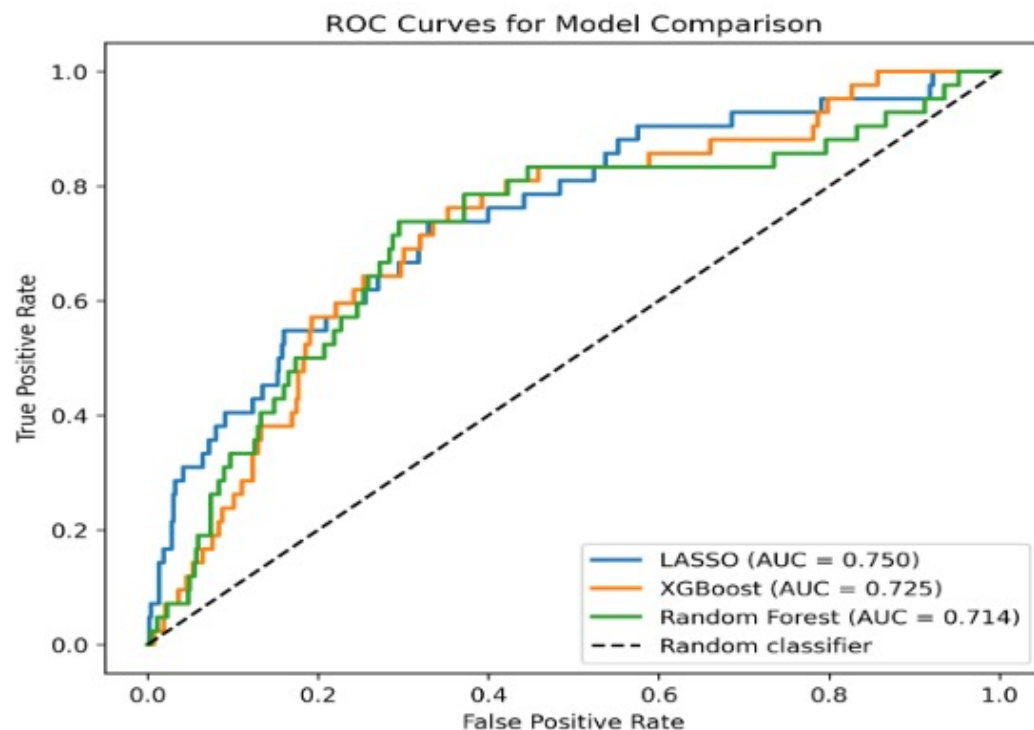
Variables	Overall PWH (N=2265)	No Cognitive impairment (n=2078)	Cognitive impairment (n=187)	P
SES				
Insurance Status				
No	97 (4.3%)	92 (4.4%)	---	0.344
Yes	2168 (95.7%)	1986 (95.6%)	---	
Annual Income (\$)				
Less 25k	1038 (45.8%)	938 (45.1%)	100 (53.5%)	0.019
25-50k	475 (21.0%)	433 (20.8%)	42 (22.5%)	
Over 50k	752 (33.2%)	707 (34.0%)	45 (24.1%)	
Education Level				
Below high school	36 (1.6%)	33 (1.6%)	---	1.000
High school or above	2229 (98.4%)	2045 (98.4%)	---	
Employment Status				
Unemployed	1269 (56.0%)	1135 (54.6%)	134 (71.7%)	<0.001
Employed	996 (44.0%)	943 (45.4%)	53 (28.3%)	
Neighborhood Environment				
Neighborhood Cohesion	3.46 (0.83)	3.46 (0.83)	3.38 (0.85)	0.177
Neighborhood Disorder	1.95 (0.62)	1.95 (0.61)	2.01 (0.67)	0.212
Neighborhood Environment Index (NEI)	4.35 (1.70)	4.36 (1.69)	4.23 (1.75)	0.316
Neighborhood Crime Safety	3.15 (0.92)	3.15 (0.92)	3.09 (0.91)	0.381
Psychosocial Factors				
Social Support	60.8 (30.2)	61.1 (30.3)	58.0 (29.4)	0.172
Instrumental Support	3.37 (1.34)	3.38 (1.34)	3.28 (1.33)	0.296
Emotional Support	3.49 (1.21)	3.50 (1.21)	3.36 (1.14)	0.112
Loneliness	17.5 (5.74)	17.4 (5.69)	18.5 (6.25)	0.016
Perceived Everyday Discrimination	19.6 (9.95)	19.4 (9.88)	21.6 (10.5)	0.007
Perceived Healthcare Discrimination	11.7 (5.16)	11.6 (5.08)	12.9 (5.93)	0.003

Perceived Stress Level				
Low	909 (40.1%)	853 (41.0%)	56 (29.9%)	<0.001
Moderate	1124 (49.6%)	1027 (49.4%)	97 (51.9%)	
High	232 (10.2%)	198 (9.5%)	34 (18.2%)	
Food and Housing				
Food Insecurity				
No	1403 (61.9%)	1297 (62.4%)	106 (56.7%)	0.142
Yes	862 (38.1%)	781 (37.6%)	81 (43.3%)	
Housing Insecurity				
No	2092 (92.4%)	1915 (92.2%)	---	0.277
Yes	173 (7.6%)	163 (7.8%)	---	
Housing Quality Concern				
No	1539 (67.9%)	1421 (68.4%)	118 (63.1%)	0.161
Yes	726 (32.1%)	657 (31.6%)	69 (36.9%)	
Healthcare Access and Utilization				
Healthcare Utilization				
No	20 (0.9%)	20 (1.0%)	0 (0%)	0.347
Yes	2245 (99.1%)	2058 (99.0%)	187 (100%)	
Healthcare Access				
No	258 (11.4%)	234 (11.3%)	24 (12.8%)	0.597
Yes	2007 (88.6%)	1844 (88.7%)	163 (87.2%)	
Others				
Religious Service Attendance	1.82 (1.96)	1.80 (1.96)	1.98 (2.03)	0.251
English Proficiency				
Not proficient/Unknown	123 (5.4%)	113 (5.4%)	---	1.000
Proficient	2142 (94.6%)	1965 (94.6%)	---	



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Results – ML Model Performance

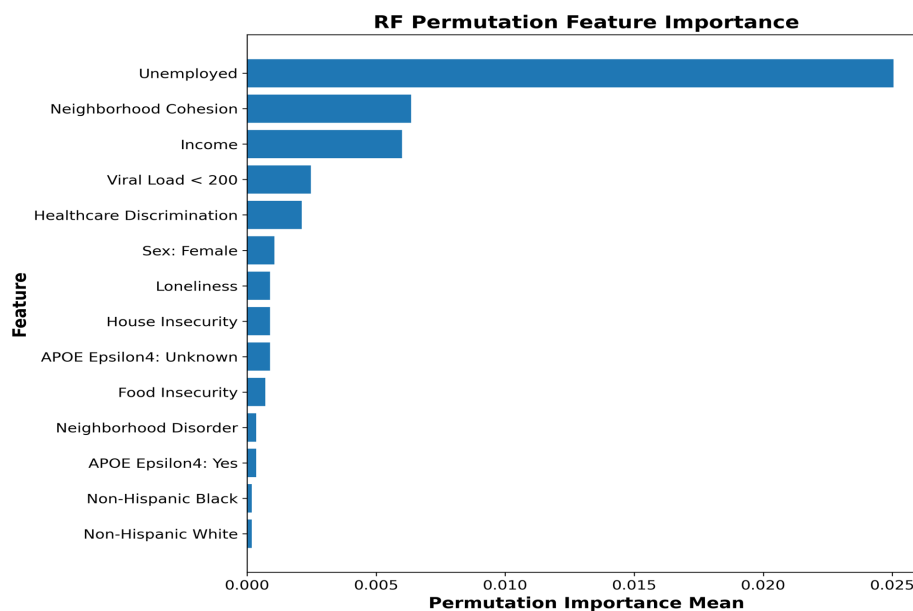
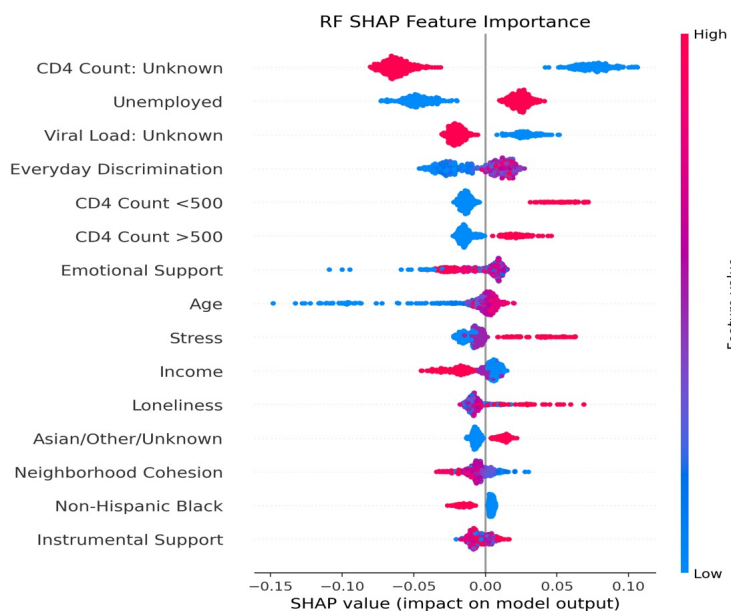


Metric	LR-LASSO	RF	XGBoost
AUROC	0.750	0.714	0.725
Accuracy	0.675	0.707	0.656
Sensitivity	0.738	0.738	0.762
Specificity	0.670	0.705	0.648
AUPRC	0.251	0.166	0.156

Three machine learning models demonstrated comparable moderate predictive performance, with LR-LASSO achieving the highest AUC (0.750) and XGBoost achieved the highest sensitivity (0.762).



Results – Random Forest Model

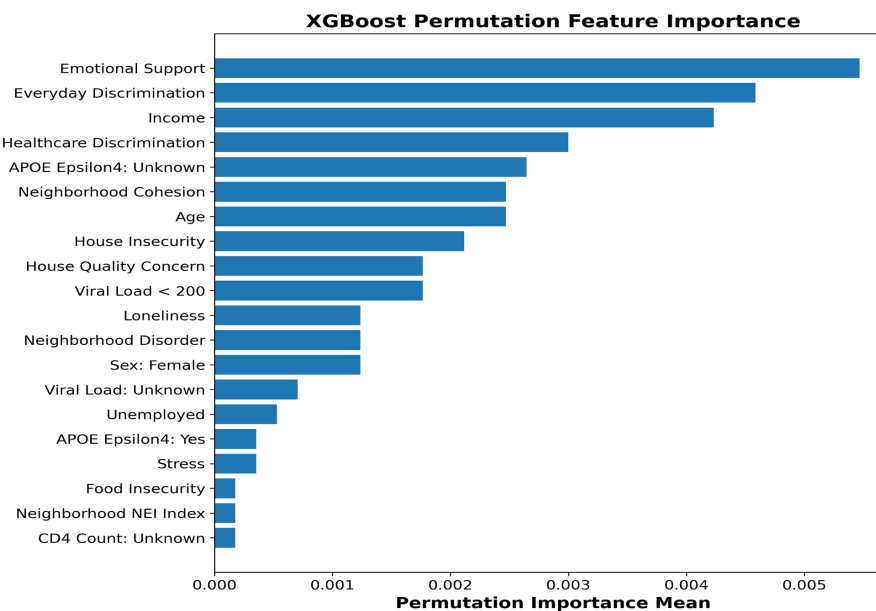
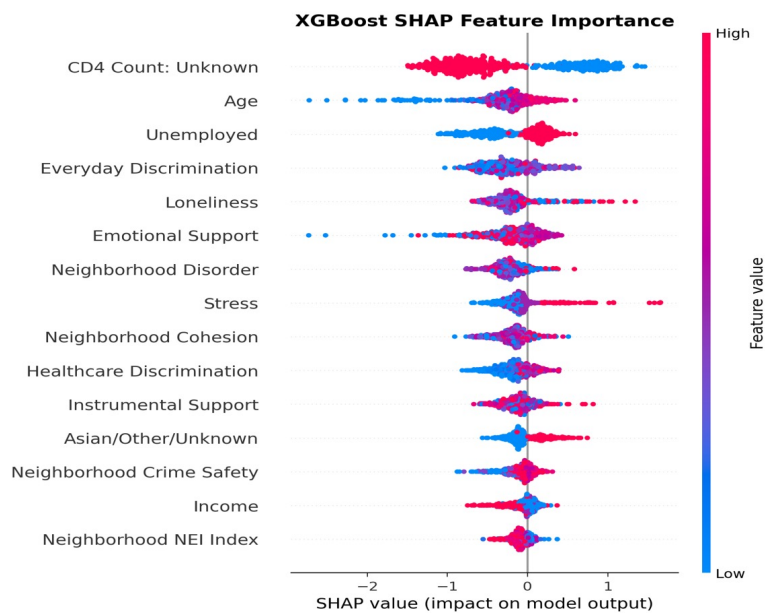


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Results – XGBoost Model



IMPLEMENTATION

- SDoH related factors
 - Employment status, income
 - Perceived stress, discrimination
 - Loneliness (e.g., some patients live alone)
- Integrated care, brain health expertise etc
- Better referral services
- Structural interventions
 - Microfinance interventions or reducing society homophobia
 - SDoH interventions: address survival or acceptance and respect
 - Basic necessities: money, food and shelter
 - Prejudice, discrimination, HIV stigma, or homophobia



LESSONS LEARNED AND FUTURE DIRECTION

- Challenges for healthcare provider recruitment
 - Busy schedule
- Incentive is important for patient participant recruitment
- Data quality of EHR: missingness
- Incentive: “Tremendous” card
- Future:
 - Another paper in preparation using HCP interviews
 - Access and utilize other statewide dataset
 - Structural interventions targeting on aging HIV population with brain health issues
 - Improve their quality of life



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THANKS!

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