Tracking Dementia in the HRS: From ADAMS to HCAP

Advanced Psychometrics Methods in Cognitive Aging Research Conference

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Health and Retirement Study (HRS)

- Ongoing, nationally representative, longitudinal, biennial survey of ~ 20,000 Americans aged > 50
- Performed at the UM Institute for Social Research, funded by the NIA and SSA
  - PI: David Weir; Co-Is: Jones and Manly
- Data collection started in 1992
- Extensive data on health, cognition, economics, work, and family from a national sample
- Face-to-face and telephone interviews (50 / 50)
- > 3,500 HRS publications by > 2,000 authors; >20,000 registered data users

HRS Survey Content

- Demographic characteristics
- Physical and functional health
- Cognitive testing
- Family structure and transfers
- Employment status, job history, and disability
- Retirement plans and perspectives
- Assets, income, and net worth
- Housing and services use
- Health insurance and pension plans
- Out-of-pocket health costs
- Links to data from employers, Medicare, NDI, VA, and SSA
- Biomarkers (2006)
  - Cholesterol, HgbA1c, CRP, Cystatin C, BP, Pulse, Peak flow, Balance, Gait
  - Venous Blood in 2016
- Genetics (2012)
  - 2.5 M SNPs on 20,000 people
HRS Longitudinal Cohort Sample Design

- AHEAD: <1924
- CODA 1924-30
- HRS 1931-41
- WB 1942-47
- EBB 1948-53

HRS INTERNATIONAL PARTNER
STUDIES AROUND THE WORLD

Harmonization tool at USC Gateway to Global Aging
g2aging.org
Tracking Brain Health in the HRS

• Modified Telephone Interview for Cognitive Status
  – orientation to day, date, month, year
  – immediate and delayed recall of 10 nouns
  – serial 7 subtraction
  – counting backwards
  – object naming
  – naming of the president and vice-president

• Verbal fluency

• Number Series

• Numeracy questions

• Speed of processing

• Self report of:
  – Memory function; ADL / IADL limitations; prior diagnosis of
    AD or dementia; medications for AD or dementia
Tracking Brain Health in the HRS (2)

• Protective and risk factors for brain health
  – CV disease risks (measured BP, obesity, health behaviors)
  – Acute medical events (stroke, sepsis, CABG => Medicare)
  – Genetics (ApoE, 2.5 million SNPs)
  – Education and leisure time activities (reading, puzzles, etc.)
  – Employment history, wealth
  – Social ties and extent of social interactions
  – Early-life factors (childhood health, parents’ education)

• Respondents represented by proxy:
  – IQCODE
  – Memory function, judgment, and change over the last 2 years
  – Doctor diagnosed AD or dementia
  – ADL / IADL limitations

• “Exit” Interview for those who’ve died
Aging, Demographics, and Memory Study (ADAMS)

• Supplemental study to the HRS funded by the NIA
• First US national, population-based study of dementia to include subjects from all regions of the country
• Initial field period: 2001 – 2005, follow-up through 2010
• 856 HRS subjects, evaluated in their homes
  – 3-4 hour neuropsychological assessment, neuro exam, informant interview, ApoE genotype
• Consensus panel diagnosis of CIND or dementia, with differential diagnosis of cause (AD, Vascular, Other)

ADAMS Estimates of 2002 US Population Prevalence, Age 71+

Normal 64%
MCI 22%
Dementia 14%

US Population, Age 71+:
Dementia 3.4 million
CIND 5.4 million
Total Pop 24.3 million

Defining Dementia using HRS-ADAMS

- Equipercentile Equating
  - Define cut-points on HRS cognitive (and other) measures that result in similar dementia prevalence estimates as the “gold-standard” ADAMS estimates
  - **Self-respondents**: 27-point HRS cognitive scale
    - 0-6 => Dementia; 7-11 => CIND
  - **Proxy-respondents**: 1) proxy assessment of memory; 2) proxy assessment of IADL limitations; and 3) interviewer assessment of cognitive impairment
    - 11-point combined scale

- Probabilistic Imputation
  - Multivariate models derived from relevant HRS cognitive, health, and sociodemographic measures that provide probability of dementia for each respondent

Dementia Annual Cost Per Case
United States, 2010

Informal Care 49%
Nursing Homes 25%
Home Care 10%
Out of Pocket 11%
Medicare 5%

Total: $50,000 per case; $200 billion nationwide

HRS: Dementia Prevalence, Age 65+

Dementia Prevalence

From ADAMS to HCAP

• ADAMS showed embedding a valid dementia diagnosis in a representative longitudinal study provides valuable information on the impact of cognitive decline on patients, families, and public programs.

• ADAMS was expensive due to traveling teams of neuropsychology technicians.

• NIA requested that the HRS team develop a less expensive method of identifying dementia in the HRS to:
  – Allow a larger sample size of in-depth cognitive assessments
  – Increase opportunities to study trends in dementia incidence / prevalence in the US
  – Increase opportunities for international comparisons of dementia prevalence and trends across the HRS family of studies.
HCAP Has Multiple Purposes

- Create, from within larger ongoing longitudinal studies, stand-alone cohorts with deep cognitive measurement
  - For epidemiology (e.g., genetic consortia)
  - For population prevalence
  - For international comparisons (e.g., cross-walk to 10/66 Brief CSI-D screener)
  - For future incidence studies by follow-up

- Goal is a replicable algorithmic diagnosis

- Use HCAP subsample to formulate rules for assigning diagnostic status to everyone in all waves of main HRS family of studies using more limited set of cognition variables

- Create public data resource so different diagnostic approaches can be used for comparison
HCAP PROTOCOL DEVELOPMENT

• 2014
  • Jan-June chose tests based on analysis of ADAMS (n=856)
  • August/Sept conducted pilot of this protocol
  • Broadened analysis to include Rush ROS/MAP (n=16,000)
  • Broadened choice of tests
  • November: Weir, McCammon, Ryan and Langa working paper on tests

• 2015
  • New version of protocol administered in two pilots
    • CogUSA (McArdle) – high functioning
    • Seattle ACT – oversample of dementia
  • Hugh Hendrie added as consultant for CSI-D harmonization
  • Harmonization meetings
    • Oct: London, England (Steptoe, Batty, Llewellyn, Brayne, Deary, Gallacher, Prince)
    • Nov: Aguascalientes, Mexico (Wong, Mejia, Sosa)
    • Dec: New Delhi, India (Lee, Bloom, Dey, Varghese)
  • Acquired 10/66 data to validate harmonization to CSI-D 10/66

• 2016
  • Final US pilot January-March (Michigan AD Center subjects)
  • HRS Interviewer trainings attended by sister study representatives
  • Sister study trainings assisted by HRS representatives
## HCAP WAVE 1 STATUS REPORT

<table>
<thead>
<tr>
<th>Country</th>
<th>Study</th>
<th>Applied</th>
<th>Funded</th>
<th>Begun</th>
<th>Completed</th>
<th>Data Released</th>
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<td>USA</td>
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<tr>
<td>Brazil</td>
<td>ELSI</td>
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</table>
NUMBER OF HCAP PARTICIPANTS*, BY STUDY

*Full cognitive testing not available for all participants; check missing data patterns!
HARMONIZATION IN HCAP

• Ex-ante design and content
• Administration, scoring
• Ex-post statistical
• Diagnostic algorithms
• Weighting for national prevalence
• Imputation of diagnosis to full study
  • (leverage ~20,000 HCAP cases to >200,000 HRS sister study participants)
**EX ANTE HARMONIZATION**

Table 4: HCAP Test Harmonization Across Studies

<table>
<thead>
<tr>
<th>Respondent Test</th>
<th>HRS-HCAP</th>
<th>ELSA</th>
<th>TILDA/NICOLA</th>
<th>HAALSI</th>
<th>LASI</th>
<th>MHAS</th>
<th>CHARLS</th>
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<tbody>
<tr>
<td>Mini-Mental State Examination (MMSE)</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>H</td>
<td>H</td>
<td>H</td>
<td>Y</td>
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<tr>
<td>HRS-TICS (3 items: Object naming; Naming President)</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>CERAD Word List Learning and Recall – Immediate</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>Semantic Fluency (Animal Naming Test)</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<td>Letter Cancellation Test</td>
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<td>Timed Backward Counting Task (from MIDUS)</td>
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<td>Community Screening Instrument for Dementia (4 items)</td>
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<td>Y</td>
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<tr>
<td>CERAD Word List Recall – Delayed</td>
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<tr>
<td>Logical Memory (Story recall) – Immediate</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>CERAD Constructional Praxis – Immediate</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>Symbol Digit Modalities Test (SDMT)</td>
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<tr>
<td>CERAD Constructional Praxis – Delayed</td>
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<td>Y</td>
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<tr>
<td>Logical Memory (Story recall) – Delayed</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>Logical Memory (Story recall) – Recognition</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>HRS Number Series</td>
<td>Y</td>
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<td>Y</td>
<td>H</td>
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<tr>
<td>Raven’s Standard Progressive Matrices</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
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<tr>
<td>Trail Making Test (Part A and Part B)</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>H</td>
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</tbody>
</table>

Y = Same test items administered; H = Similar test items administered

<table>
<thead>
<tr>
<th>Coverage of HRS-HCAP Tests (% Y)</th>
<th>100</th>
<th>100</th>
<th>100</th>
<th>78</th>
<th>67</th>
<th>56</th>
<th>39</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coverage of HRS-HCAP Tests (% linear composite score variance explained by Y tests)</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>96</td>
<td>96</td>
<td>93</td>
<td>87</td>
</tr>
</tbody>
</table>
HCAP Informant Report

• Valuable complement to testing
• Report on cognitive changes, activity levels and limitations
• HRS HCAP includes
  – Blessed
  – Jorm IQCODE
  – CSI-D
• Somewhat redundant, but permits harmonization to studies with more limited data
## HRS HCAP RESPONSE RATE, BY COGNITIVE STATUS AT HRS 2016 INTERVIEW

<table>
<thead>
<tr>
<th>HRS status</th>
<th>Both</th>
<th>R only</th>
<th>Inf only</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>High normal</td>
<td>73.8</td>
<td>5.8</td>
<td>0.1</td>
<td>79.7</td>
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<tr>
<td>Low normal</td>
<td>69.0</td>
<td>7.2</td>
<td>3.1</td>
<td>79.3</td>
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<tr>
<td>MCI</td>
<td>67.8</td>
<td>9.8</td>
<td>2.9</td>
<td>80.5</td>
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<tr>
<td>Dementia</td>
<td>50.8</td>
<td>5.7</td>
<td>16.6</td>
<td>73.1</td>
</tr>
<tr>
<td>All</td>
<td>68.6</td>
<td>7.1</td>
<td>3.4</td>
<td>79.0</td>
</tr>
</tbody>
</table>
LASI-DAD Sample

• Sampling strategy
  • Oversampling of high risk of cognitive impairment
    • The sample consists of about ½ high risk of cognitive impairment and ½ not high risk
      ▪ Risk of cognitive impairment is based on the LASI main wave
  • Select the state where a partner hospital is located and set a target sample size based on the main LASI sample size within each state
  • Randomly select age 60+ with equal number of high and not high risk of cognitive impairment for the target sample size within each state

• Released to HCAP in batches, after 2-month interval from the main LASI

• Response rate ~ 83%

• Target sample size 3,200
LASI-DAD Study Sites

India

Phase 1 | Phase 2
---|---
State | Sample | State | Sample
Delhi | 350 | Maharashtra | 350
Kerala | 350 | West Bengal | 300
Rajasthan | 251 | Assam | 200
Karnataka | 251 | Telangana | 250
Tamilnadu | 300 | Odisha | 200
Uttar Pradesh | 86 | Jammu & Kashmir | 150
Total | 1588 | | 1450
MHAS Mex-Cog Sample

- Sample selected from 8 of 32 states
  - States selected for coverage of urban/rural, cost/efficiency of survey operations
  - 3,250 of MHAS 2015 respondents, aged 55 and older, with direct interview or proxy for health reasons
  - Full sample – single and coupled households

- Response rate ~70% of selected

- Effective sample size: 2,265 (25.1% of 55+ in MHAS 2015)
  - Both cognitive and informant: 1849
  - Cognitive assessment only: 193
  - Informant only: 223
Conclusions

• Population-based studies of dementia are especially important now given aging of populations

• HRS-HCAP is designed to leverage existing HRS family of nationally-representative studies

• The goal is to provide publicly-available data on comparable dementia diagnostic classifications to help track dementia burden on patients, families, and health systems in countries around the world
HRS-HCAP Funding
National Institute on Aging
Social Security Administration

More HRS-HCAP Information

HRS website
Gateway to Global Aging website