

Maximizing Participation in MIDUS

- Incentives
- Newsletters
- Birthday cards



Giving Back
(building rapport)

Also:

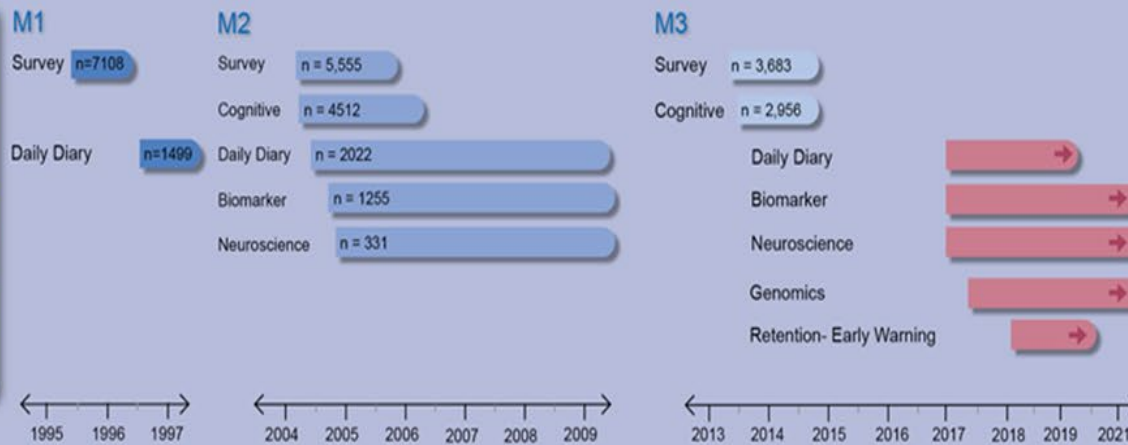
- ❖ Refielding Effort (SAQs, Cognitive)
- ❖ REW (Retention/Early Warning Project
(re-instating previous attriters))

The Headache of Consent

MIDUS Design

(N = 11,867, aged 25-74)

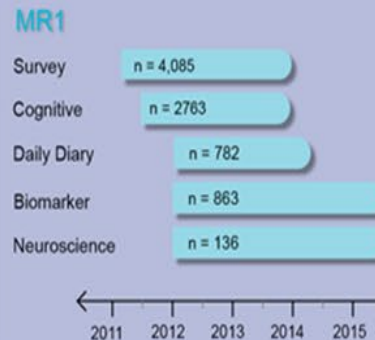
Core Samples (RDD, Twins, Siblings)



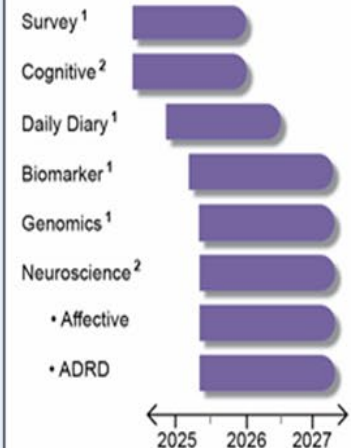
KEY

- M1- MIDUS Baseline Study
- M2- 1st MIDUS Follow-up
- M3- 2nd MIDUS Follow-up
- M4- 3rd MIDUS Follow-up
- MR1- MIDUS Refresher Baseline
- MR2- 1st Refresher Follow-up
- Current data collection

MIDUS Refresher Expansion



M4

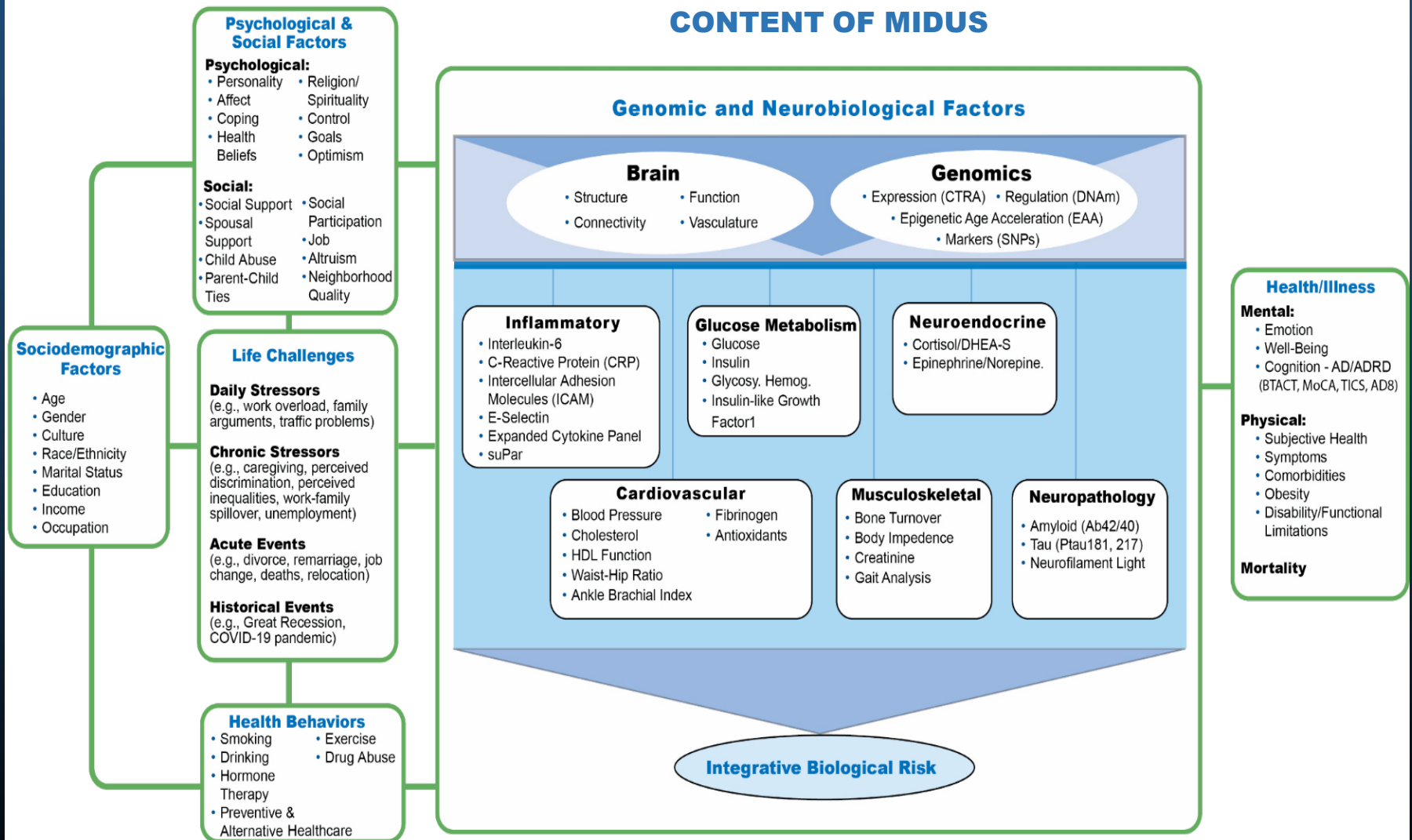


MR2



MIDUS Assessments

CONTENT OF MIDUS



MIDUS Response Rates

****M3 Refielding:**
456 Completes
[193 SAQ,
263 BTACT]

❖ **INCENTIVES**
SAQ: \$10 + \$75
COG: \$10 + \$50

	Baseline	1 st Follow-up	2 ND Follow-up
Core (National)			
Phone interview	70%	75%	75%
SAQ	89%	81%	83(89)%**
Cognitive	NA	85%	82(90)%**
Core (Milwaukee)			
Personal interview	71%	78%	
SAQ	70%	84%	
Cognitive	52%	85%	
Refresher (National)			
Phone interview	59%		
SAQ	74%		
Cognitive	71%		
Refresher (Milwaukee)			
Personal interview	48%		
SAQ	58%		
Cognitive	42%		

Longitudinal response rates adjusted for mortality.

** Response rates in parentheses adjusted for **Refielding Effort**

MIDUS Refresher & CPS (2012)

Message

- Despite 59% RR, Refresher data (MR) align well with CPS, except for education
- Sampling and post-strat weights adjust data

MIDUS Refresher	<u>CPS (Oct, 2012)</u> (N=81,379) %	<u>Unweighted MR data</u> (N=3,573) %	<u>Weighted MR data</u> (N=3,573) %
SEX			
Male	47.9	48.2	47.9
Female	52.1	51.8	52.1
RACE			
White	82.5	84.2	83.2
Black	9.7	9.5	9.8
Others	7.8	6.3	7.0
AGE			
25-34	20.9	19.4	20.9
35-44	20.9	20.3	20.9
45-54	23.3	20.4	23.3
56-65	21.3	19.9	21.3
66-75	13.6	20.0	13.6
EDUCATION			
12 years or less	39.2	23.2	39.2
13 – 15 years	27.6	30.7	27.7
16 years or more	33.2	46.1	33.1
MARITAL			
Married	62.5	64.0	62.6
Separated	2.3	2.1	2.2
Divorced	12.9	13.4	12.9
Widowed	3.7	5.6	3.7
Never Married	18.6	15.0	18.6

Milwaukee (MKE) Recruitment

(n = 1,200: MKB = 592, MKR = 508)

Why MKE?

➤ Bring AA's to biomarker/neuro data collection in Madison

How Recruit?

➤ Probability sample of MKE HHs stratified by age, gender, & SES

	Baseline	1 st Follow-up	2 nd Follow-up
Core (National)			
Phone interview	70%	75%	75%
SAQ	89%	81%	83(89)%**
Cognitive	NA	85%	82(90)%**
Core (Milwaukee)			
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Cognitive	42%		

Longitudinal response rates adjusted for mortality.

** Response rates in parentheses adjusted for **Refielding Effort**

Findings linked to Milwaukee Sample

Habitual sleep as a contributor to racial differences in cardiometabolic risk

David S. Curtis^{a,1}, Thomas E. Fuller-Rowell^b, Mona El-Sheikh^a, Mercedes R. Carnethon^b, and Carol D. Ryff^c

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Edited by Susan Redline, Brigham and Women's Hospital, Boston, MA, and accepted by Editorial Board Member Gregg L. Semenza June 28, 2017 (received for review November 3, 2016)

Insufficient and disrupted sleep is linked with cardiovascular and metabolic dysregulation and morbidity. The current study examines the degree to which differences in sleep between black/African American (AA) and white/European American (EA) adults explain racial differences in cardiometabolic (CMB) disease risk. Total sleep time and sleep efficiency (percent of time in bed asleep) were assessed via seven nights of wrist actigraphy among 426 participants in the Midlife in the United States Study (31% AA; 69% EA; 61% female; mean age = 56.8 y). CMB risk was indexed as a composite of seven biomarkers [blood pressure, waist circumference, hemoglobin A1c (HbA_{1c}), insulin resistance, triglycerides, HDL cholesterol (HDL-C), and C-reactive protein]. Covariates included sociodemographic characteristics and relevant health behaviors. Results indicated that AAs relative to EAs obtained less sleep (341 vs. 381 min) and had lower sleep efficiency (72.3 vs. 82.2%) (P values < 0.001). Further, 41% and 58% of the racial difference in CMB risk was explained by sleep time and sleep efficiency, respectively. In models stratified by sex, race was indirectly associated with CMB risk via sleep time and efficiency only among females (explaining 33% and 65% of the race difference, respectively). Indirect effects were robust to alternative model specifications that excluded participants with diabetes or heart disease. Consideration of sleep determinants and sleep health is therefore needed in efforts to reduce racial differences in CMB disease.

health disparities | race | sleep | cardiometabolic disease | health behaviors

Therefore the primary aim of the current study was to test the degree to which differences in habitual sleep explain racial differences in CMB disease risk. Data were derived from 426 AA and EA adults from the Midlife in the United States (MIDUS) study who participated in a sleep substudy. Total sleep time and sleep efficiency (i.e., the percentage of the time in bed spent sleeping) were measured over seven nights using actigraphy—a watch-like activity monitor that has good correspondence with polysomnography (22). CMB risk was measured as a composite of ideal, borderline high, and high (coded as 0, 1, and 2, respectively) levels of waist circumference, hemoglobin A1c (HbA_{1c}), insulin resistance [homeostatic model assessment of insulin resistance (HOMA-IR)], blood pressure, triglycerides, HDL cholesterol (HDL-C), and C-reactive protein (CRP) (Table 1) (23–25). CMB risk scores were averaged across the biomarkers so that total scores ranged from 0 to 2. Additional models were fit to examine whether associations between sleep and CMB risk varied by demographic factors (race, sex, and age) and, given that AA–EA differences in obesity and diabetes are larger for females than for males (26, 27), whether mediation of racial differences in CMB risk varied by sex. To reduce the likelihood of reverse causality, we also tested study hypotheses among participants without heart disease or diabetes.

Results

Sample descriptive statistics are listed by race in Table 2. Race differences were identified in several of the sociodemographics, health behaviors, and CMB markers. Notably, AAs obtained nearly 40 fewer minutes of sleep and had 10% lower sleep efficiency than

- AA's had poorer sleep (less time, lower efficiency) compared with EA's (actigraphy)
- Race differences in cardiometabolic (CMB) risk were partially explained by sleep time and efficiency

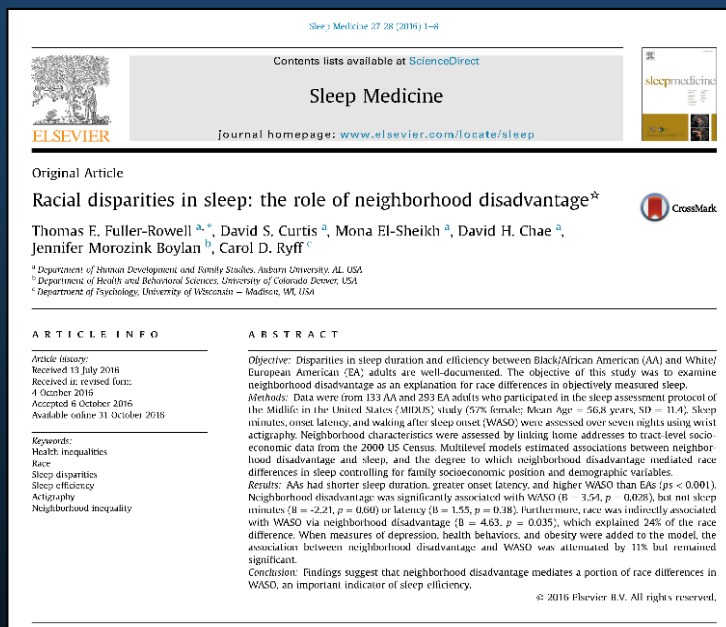
Curtis et al., 2017, PNAS

Unpacking Race Differences in Sleep

Neighborhood disadvantage (income, poverty rate, public assist, educ level) mediated race differences in waking after sleep onset (WASO)

Higher perceived discrimination → more sleep difficulties

- Discrimination attenuated difference in sleep between whites & nonwhites



Fuller-Rowell et al., 2016,
Sleep Medicine



Owens et al., 2017,
Psychosom Medicine

REW (Retention-Early Warning) Project

Objectives

1. Re-instate 500-600 attriters from MIDUS 2 and MIDUS 3 (~20% of attriter pool)
 - Using high incentives and state of the art methods (UW Survey Center)
2. Collect data [home interviews] on → mental/physical health, biomarkers, stressors
 - 60 min personal interview
 - 10 min cognitive interview
 - select biomarkers
 - 20-page SAQ

COMPLETES → 651

Background of REW Project

Who Participates? Accounting for Longitudinal Retention in the MIDUS National Study of Health and Well-Being

Journal of Aging and Health
22(3) 307-331
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DOI: 10.1177/0898264309358617
<http://jah.sagepub.com>
SAGE

Barry T. Radler¹ and Carol D. Ryff¹

Abstract

Objectives: This article uses data from MIDUS (Midlife in the United States), a national study of Americans ($N = 7,108$), to investigate factors that predict longitudinal retention. With its extensive age range (25-75 at Time 1) and long-term design (9- to 10-year survey interval), MIDUS is useful for investigating common sociodemographic and health predictors of continuing participation. **Method:** The authors conducted logistic regression analyses of baseline sociodemographic and health variables predicting retention. Select interaction terms examined the interplay between targeted variables. **Results:** Consistent with prior research, higher retention rates were found among Whites, females, and married individuals as well as those with better health and more education. Interaction analyses further clarified that (a) health status better predicted retention among older compared to younger respondents and among women compared to men, (b) marital status better predicted retention among Whites compared to non-Whites and among women compared to men, and (c) economic status better predicted retention among those with poorer functional health status. **Discussion:**

- Attrition in longitudinal studies is selective (age, gender, race, marital status, SES)
- Interactions among above variables
- Sociodem's interact with psychosocial var's (e.g., control beliefs, perceived discrimin)

Radler & Ryff, 2010

*Do these combinations of
vulnerability predict poorer
health over time?
[representativeness + science]*

REW Initial Findings

Article

Who Returns? Understanding Varieties of Longitudinal Participation in MIDUS

Jieun Song, PhD¹ , Barry T. Radler, PhD¹, Margie E. Lachman, PhD², Marsha R. Mailick, PhD¹, Yajuan Si, PhD³ , and Carol D. Ryff, PhD¹

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Abstract

Objectives: This study describes a major effort to reinstate dropouts from the MIDUS longitudinal study and compare baseline characteristics among subgroups of participants to better understand predictors of retention, attrition, and reinstatement. **Methods:** All living dropouts were contacted, and 651 reinstated participants were interviewed in person (31.4% response rate). Age, gender, education, marital status, parental status, and physical and mental health were compared among the following groups: longitudinal sample, reinstated sample, those fielded for reinstatement who did not return, and those who dropped out at the 2nd or 3rd wave. **Results:** Multivariate analyses revealed that reinstated participants were younger, male, unmarried, and less educated and had children at baseline compared to longitudinal participants. Reinstatement was unsuccessful among those with poorer mental health at baseline compared to longitudinal participants. **Discussion:** This study informs reinstatement efforts, adjustment for attrition bias, and use of *post-baseline* data to examine aging consequents of early life vulnerability.

Keywords

reinstatement, retention, attrition, baseline characteristics

Introduction

Longitudinal aging research, particularly when conducted with national samples where representativeness is of concern, demands careful attention to initial recruitment of participants as well as to who stays in the study over time (retention) and who drops out (attrition). These tasks are important for maintaining sample representativeness over time, and they may also matter for evaluating whether attrition is biasing the longitudinal findings that are generated. This study describes

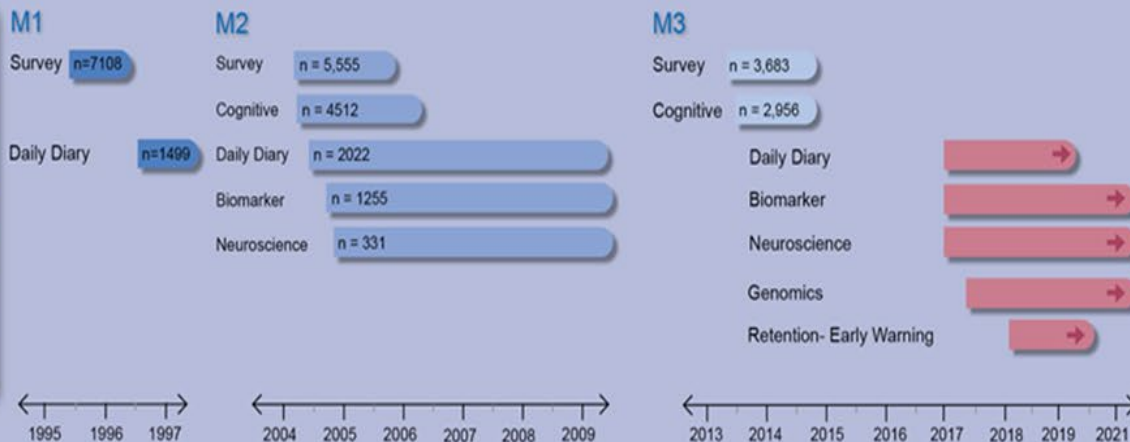
Jacobsen et al., 2020; Lillard & Panis, 1998; Powers et al., 2015; Radler & Ryff, 2010; Tolonen et al., 2006). In contrast, attrition tends to be higher among youngest and oldest members of the population as well as minorities (Cacioppo & Cacioppo, 2018; Goudy, 1985; Jacobsen et al., 2020; Radler & Ryff, 2010; Tolonen et al., 2006; Zabel, 1998). Attriters also tend to have poorer health than respondents (Akasaki et al., 2020; Banks et al., 2011; Gardiner et al., 2015; Jacobsen et al., 2020; Norris, 1985; Siegler & Botwinick, 1979; Streib, 1966). Health-related behaviors such as alcohol

- 651 participants returned (31.4% RR)
- 29% of REW sample were minorities
- Those who returned: more likely to be younger, male, unmarried, less educated and a parent compared to longitudinal sample

Song et al., 2021

Multi-Project Participation

Core Samples (RDD, Twins, Siblings)

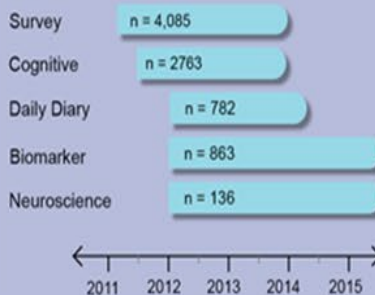


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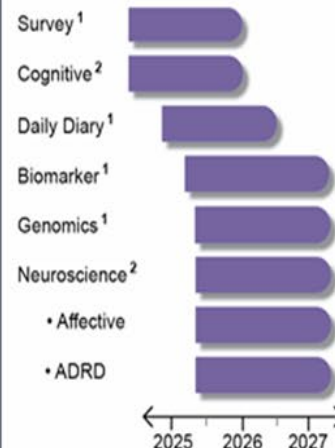
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MIDUS Refresher Expansion

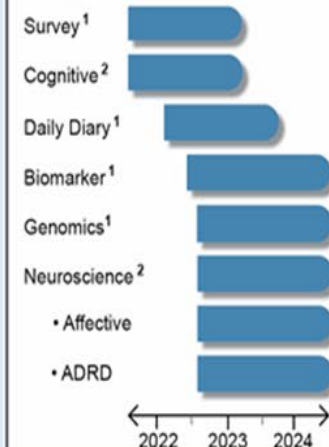
MR1



M4



MR2



What Is Asking Too Much?

- Issues of respondent burden
- M3 return rates for those who previously completed M2 survey plus another project:
 - ❖ *75% from cognitive project returned*
 - ❖ *85% from diary project returned*
 - ❖ *92% from biomarker project returned*
 - ❖ *94% from neuroscience project returned*
- Retention at M3 was higher among those who participated in multiple projects at M2
- asking more → coming back

Facilitating Participation in Biomarker Project

- 2-day clinic visit + travel
- Overcoming barriers to participation:
 - ❖ *Flexible scheduling (weekends)*
 - ❖ *Cultivate trust by listening and addressing participant concerns*
 - ❖ *Cover all travel costs + companion travel, if necessary*
 - ❖ *Cover other expenses (childcare, pet care, farm help)*
 - ❖ *INCENTIVE: \$200 at end of visit*

Giving Back Via Newsletters

16 Topics

Why Do You Participate?

- interested in research
- contribute to science
- \$\$, health information



Midlife in the United States

A National Longitudinal Study of Health & Well-Being

Funded by the National Institute on Aging

Home | About The Study | For Researchers | For General Public | Contact

MIDUS Newsletters

We periodically create MIDUS newsletters and share them with our research participants. The newsletters provide summaries of some key findings that have resulted from the MIDUS study. (You will need Acrobat Reader to view them.)



Purpose in Life

This newsletter is about the significant health benefits that are associated with feeling that your life has purpose and meaning.

.....learn more



Cancer Survivors in MIDUS

This newsletter is about one of the special populations MIDUS has been following- the growing number of people who have survived cancer.

.....learn more



Sleep & How It Matters for Health

MIDUS is linking sleep to many aspects of health, such as pain, obesity, and well-being

.....learn more



Inflammation & Health

Inflammation seems to interact with psychological, social & behavioral factors to put us at risk for multiple aging-related illnesses

.....learn more



Inequality & Health

Inequality in America has become an important issue in public discussions and in many people's lives. It is also the focus of scientific attention and a major theme within the MIDUS study.learn more



Managing Emotions

MIDUS is advancing knowledge of how emotions are linked with becoming ill, and how effective management of emotions can promote good health.learn more

e.g., Purpose in Life and Health

Purpose in Life

MIDUS
Midlife in the United States
A National Study of Health & Well-Being

The Benefits of a Purposeful Life

Viktor Frankl was one of the first to write about the importance of purpose in our lives. He published "Man's Search for Meaning" in 1946, which described his 3-year ordeal in Nazi concentration camps. The book went on to be read by millions of people all over the world.

Trained as a psychiatrist, Frankl detailed how he kept himself strong by focusing on beautiful things from his past, such as how much he loved his wife, as well as on envisioning a future in which he would talk with others about what mattered in his survival. Central to his insights was the realization that although he could not control what was happening to him, he could choose his response to it. Frankl which was to try to find meaning in the experience. Frankl went on to create logotherapy – an approach to treating emotional distress by helping people find or create purpose and meaning from their adverse experiences.

A half century later, the benefits of purposeful life engagement have entered health research in a dramatic way. We highlight here some findings from multiple studies, including MIDUS, that have documented the health benefits of perceiving that one's life has purpose and meaning. We are sending you this newsletter with our thanks, as a way of showing how you are making a meaningful difference in our research by participating in the MIDUS study.

Sincerely,
Carol D. Ryff, Director
MIDUS National Study of Health & Well-Being

What Happens to Purpose in Life as People Age?

- MIDUS findings from the first national survey, as well as from subsequent follow-up surveys, showed that purpose in life declines for some people as they grow older.
- However, data also showed a lot of variation among older participants, meaning that some are able to maintain high levels of purposeful engagement even into old age. [Ryff, 1999; Ryff & Singer, 2020]

100

Importantly, those who maintain a sense of purpose are reaping significant health benefits, including living longer.

What Does It Mean to Have Purpose?

People with purpose have goals that they feel make their life worth living.

They have beliefs about what matters that provide directions for how to live.

Purpose gives meaning, not only to their present, but also to their past and future.

Purpose in Life

MIDLIFE IN THE UNITED STATES: A NATIONAL STUDY OF HEALTH AND WELL-BEING

FONDED BY THE NATIONAL INSTITUTE ON AGING

- What is purpose in life?
- How does it matter for health?
 - Longevity, Alzheimer's, CVD, inflammation
- Activities that nourish PIL:
 - Volunteering, social connection, work engagement, religion

The Headache of Consent

**We don't decide....
IRBs do**

IRBs sometimes get in way of multiple
contact attempts and refusal conversion

MIDUS Consent Procedures

- Separate consents for each project
(some proj's have multiple consents)
- Variability across IRBs (within & between institutions)
 - we are instructed what verbiage to use
 - emphasis on protecting institution against legal liability

❖ *“Informed Consent”*

documents that confuse more than inform
e.g. biomarker project – 9 pages
of complex text

Required Text

- *“There is no direct benefit to you for participating in this research study.”*
[nonetheless, we provide health info – blood pressure, cholesterol, body mass index, bone scans, etc.]
- *“If a (genetic) result gets into your medical record...., it could lead to loss of health insurance, difficulty obtaining insurance, or an increase in premiums. If your employer or a potential employer becomes aware it could lead to job loss or difficulty obtaining a new job.”*
- *“In the event that you are physically injured as a result of participating in this research, emergency care will be available. You will, however, be responsible for the charges for the emergency care.”*

Recap of Key Points

Consent Issues Are Complicated

High Participation/Retention in MIDUS has been enhanced by:

- ❖ Using targeted INCENTIVES within all projects
- ❖ Cultivating rapport/giving back (newsletters)
- ❖ Using personal interviews in Milwaukee & REW
- ❖ Careful pacing of “asks” going from project to project

Wide-Ranging Engagement with MIDUS

24,000+
users

1,500+
pubs

www.midus.wisc.edu

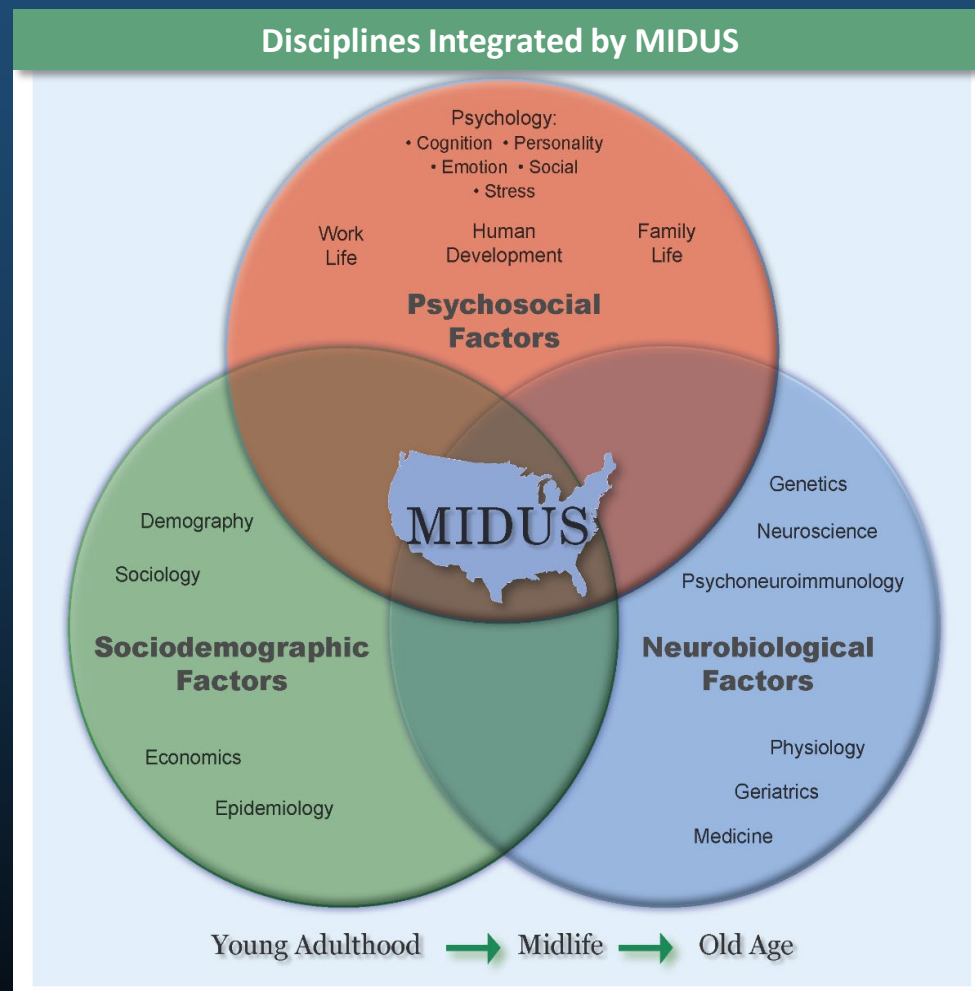
MIDUS Publications by Topic

TOPIC	#	TOPIC	#
Affect/Emotion	360	Non-normative Parenting	22
Aging	343	Obesity/Weight	98
Allostatic Load	59	Occupation & Employment	137
Altruism	52	Perceived Discrimination	81
Biomarkers	375	Personality	249
Cancer	21	Physical Health	602
Childhood/Early Life	164	Psychological Well-being	373
Chronic & Acute Challenges	123	Purpose in Life	34
Cognitive Function	126	Race & Ethnicity	172
Culture/Country	93	Religion & Spirituality	63
Daily Experiences	200	Resilience	52
Gender	217	Sense of Control	118
Genetics & Twins	120	Sexuality	28
Health Behaviors	216	Sleep	77
Historical Context/Recession	29	Social Inequalities/SES	184
Mental Illness	220	Social Relationships/Support	377
Mortality	58	Social Responsibility	60
Neighborhood	37	Volunteering	44
Neuroscience	24	Work and Family	54

Getting All Disciplines to Care About Population Representativeness

- Bringing sociodem factors to small-sample science
- Bringing psychsoc & neurobiolog factors to population science

WHY?



Contemporary Societal Challenges: Health Inequalities - Exacerbated by Pandemic

*High and Rising
Mortality Rates
Among
Working-Age Adults
(2021)*
Washington, D.C.:
National Academies
Press

BSR - NIA



NEJM 2021

Thanks for listening

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<http://midus.wisc.edu>