

## RESEARCH ARTICLE

# Spouses of individuals living with mild cognitive impairment or dementia in the United States: A descriptive, population-based study

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## Abstract

**BACKGROUND:** Little is known about the population of individuals who live with a spouse with cognitive impairment (CI) or dementia.

**METHODS:** Using the US Health and Retirement Study, 2000 to 2018, we estimated the population of adults  $\geq 50$  years old co-residing with a spouse with probable CI/dementia. We described their socio-demographic and health characteristics and quantified socio-demographic inequities.

**RESULTS:** Among community-dwelling adults  $\geq 50$  years old, 6% of women and 4% of men co-resided with a spouse with probable CI/dementia. Among those who were married/partnered, the prevalence of spousal dementia was greater for Black and Hispanic adults compared to their White counterparts, and for those with lower versus higher educational attainment. Among spouses, activities of daily living disability, depression, and past 2-year hospitalization was common.

**DISCUSSION:** Millions of older adults, disproportionately Black and Hispanic people and people with lower levels of educational attainment, live with a spouse with CI while also facing their own major health challenges.

## KEYWORDS

dementia, epidemiology, family, health equity, mild cognitive impairment, spouses

## 1 | INTRODUCTION

The onset of cognitive impairment (CI) and dementia can be catastrophic for the whole family, with particularly acute impacts on the lives of spouses or partners. Many studies have described the characteristics and outcomes of individuals who are caregivers for their spouses or

partners with CI and dementia.<sup>1–3</sup> However, these studies may not fully capture the population of mid- and late-life adults whose spouses or partners (hereafter “spouses” for simplicity) have CI or dementia, many of whom will not have taken up caregiving responsibilities. In addition, the caregiver-focused literature may miss many individuals who cannot provide spousal care due to their own health conditions, including

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physical disability or dementia, but who may nevertheless be impacted by their spouse's health status. A better understanding of the overall prevalence of co-residing with a spouse with CI or dementia in the United States and the characteristics of this population could inform efforts to jointly address the health and well-being of people with dementia and their spouses<sup>4</sup> and/or policies that explicitly or implicitly rely on spousal caregiving.<sup>5</sup>

The well-documented racial, ethnic and socio-economic inequities in dementia prevalence and incidence<sup>6–12</sup> likely translate to a much higher prevalence of Black or Hispanic/Latino (hereafter Hispanic for brevity) adults and/or those with lower educational attainment co-residing with a spouse with CI or dementia, although this has not been quantified. The prevalence of spousal dementia may also vary by sex, although the potential direction of this difference is unclear. Socio-demographic patterns in co-residing with a spouse with CI or dementia will also be informed by late-life marital status dynamics—which are themselves informed by a complex set of factors, including life expectancy—as well as differences in the likelihood of remaining in the community. For example, racially and ethnically minoritized individuals are more likely to remain in the community through late life rather than entering assisted living or nursing home facilities,<sup>13,14</sup> which may partially inform the probability of co-residing with a spouse with CI or dementia. This may also be true for individuals with lower socio-economic status (e.g., lower levels of educational attainment), although the literature on socio-economic differences in nursing home use in the United States is mixed.<sup>15–17</sup>

In the present study, we estimated the prevalence of co-residing with a spouse who has probable CI or dementia in the United States in the first decades of the twenty-first century. We additionally describe this important group across socio-demographic, economic, and select health-related domains. Finally, we estimated the magnitude of inequities in the prevalence of co-residing with a spouse with probable CI or dementia by sex, race, ethnicity, and educational attainment. We note that this is a descriptive study that does not aim to evaluate a causal question, but instead to quantify and characterize this critical population to inform programmatic and policy priorities.<sup>18,19</sup>

## 2 | METHODS

### 2.1 | Data

We used data from the Health and Retirement Study (HRS), an ongoing nationally representative longitudinal study of community-dwelling adults  $\geq 50$  years and their spouses or non-marital partners of any age. The HRS has been conducted every 2 years since 1992, with a new cohort of participants added every 6 years. For this paper, we use the RAND HRS Longitudinal File 2018; we restricted our analyses to waves conducted between 2000 and 2018; the most rigorous dementia classification algorithms have not been extended to earlier waves.

Given the potential utility (e.g., for public policy and health priority setting) of knowing the overall population prevalence of co-residing with a spouse who has probable CI or dementia among all adults  $\geq 50$  years regardless of marital status, we first generated these estimates.

### RESEARCH IN CONTEXT

- 1. Systematic review:** The authors reviewed the literature using traditional (e.g., PubMed) sources as well as meeting abstracts and statistical reports. While we cite the substantial literature on the health impacts of dementia on spousal caregivers, we are not aware of prior research that has quantified the population of individuals living with a spouse or partner with dementia.
- 2. Interpretation:** Our findings establish that millions of older adults in the United States live with a spouse who has probable cognitive impairment (CI) or dementia. These spouses have important health considerations of their own, many of which could limit caregiving capacity. Among those who are married or partnered, there is also a substantial inequity in the prevalence of living with a spouse with probable CI or dementia by sex, race, ethnicity and educational attainment, in line with well-documented inequities in the burden of CI/dementia.
- 3. Future directions:** Future research should continue to comprehensively document the demographics of spouses of individuals with CI or dementia. Such studies should include spouses who are not able to provide care due to their own health conditions and may therefore be excluded from studies focused on spousal caregivers. Finally, future research should continue to track inequities in the prevalence and experiences of spousal CI or dementia.

The derivation of this analytic sample is described in [Appendix Text S1](#) in supporting information. However, these estimates conflate marital status and the burden of CI or dementia. We therefore focused our primary analyses, including analyses of population-level inequities, on those respondents who were married to or partnered with a person  $\geq 65$  years old.

To construct this primary analytic sample, we began with all co-residing and community-dwelling HRS spouse dyads between 2000 and 2018 HRS waves. We then restricted the analytic sample to dyads in which the index respondent was  $\geq 50$  years and their spouse was  $\geq 65$  years. This age restriction for spouses is driven by the validity of dementia classification algorithms in HRS.<sup>20</sup> If spouse dyads appeared in the HRS at multiple waves, only those waves in which both members co-resided in the community and met the age criteria were included in the analysis.

We further restricted the sample to spouse dyads with available information relevant for dementia classification and socio-demographic characteristics. We retained observations for which a proxy informant completed the interview because the respondent was not able to do so. This was critical, as CI was a major reason that HRS respondents relied on proxy informants. Many in this group would likely be excluded from studies focused on spousal caregivers but are

important to include as part of the overall population of individuals co-residing with a spouse with CI/dementia. Based on these criteria, a total of 7352 unique women (30,649 person/wave observations) and 6341 unique men (24,769 person/wave observations) were included in the weighted sample (see Figure S1 in supporting information for Analytic Sample Flow Chart). We additionally present the descriptive characteristics of those experiencing spousal dementia; that is, we limited the subset of observations to respondents who met the criteria for our analytic sample and also had a spouse who met the criteria for probable CI or dementia.

## 2.2 | MEASURES

### 2.2.1 | CI and dementia

For our primary analyses, we classified probable CI and dementia with the Langa-Weir<sup>20</sup> (LW) algorithm, which uses respondents' performance scores on a version of the Telephone Interview for Cognitive Status and proxy-reported information on CI and functional limitations. LW classifies HRS respondents and spouses into three categories: normal, CI without dementia, and dementia. We grouped those who were classified as having probable CI or dementia (vs. normal cognition).

In sensitivity analyses, we considered an alternative dementia classification algorithm; the results from recently developed classifications suggest that the LW algorithm may overestimate CI and dementia among Black non-Hispanic and Hispanic HRS respondents. We selected the recently developed Hudomiet, Hurd, and Rohwedder (HHR) algorithm, which has been developed for the 2000 to 2016 waves, and classifies probable dementia, CI, and normal cognition based on the creation of a longitudinal latent cognitive ability score with calibration to detailed population subgroups, including by sex/gender, race/ethnicity, and educational attainment.

### 2.2.2 | Socio-economic and health characteristics

We described the following characteristics for respondents co-residing with a spouse with probable CI or dementia: current age, country of birth (United States vs. other) and race and ethnicity (Black non-Hispanic [hereafter Black for brevity], Hispanic, and White non-Hispanic [hereafter White for brevity]). While we report results for those whose race or ethnicity was not specified, we did not incorporate these findings into our overall interpretation and conclusions given the substantial heterogeneity of racial/ethnic backgrounds among this group. We also described respondents' level of educational attainment, total number of living children, household size, homeownership status (yes/no), and current labor force status (works full time, works part-time, unemployed, partially retired, retired, disabled, or not in the labor force). All models were stratified by respondents' self-reported sex/gender. In the HRS questionnaire, sex and gender are used interchangeably and it is not possible to differentiate sex assigned at birth

from gender identity.<sup>21</sup> For parsimony, we refer to "sex" going forward, but acknowledge the need for improved questions on sex and gender that would allow for greater specificity in future research.<sup>21</sup>

We additionally described respondents' physical and mental health status, with data collected from each study wave. Specifically, we examined the prevalence of difficulty with the ability to perform basic activities of daily living (ADL; i.e., dressing, walking, bathing, eating, getting in/out of bed, and toileting) and instrumental activities of daily living (IADL; i.e., preparing meals, shopping, using the phone, taking medications, and managing money) as well as the average number of difficulties. We also calculated the prevalence of any hospitalization in the 2 years prior to the interview and the average number of recent hospitalizations.

For respondents who completed direct interviews (i.e., without a proxy informant), we described current mental health using the Center for Epidemiological Studies Depression (CES-D) eight-item scale; we classified elevated depressive symptoms based on a cut of > 4 on the CES-D scale. In addition, we examined the prevalence of loneliness with the loneliness item ("felt lonely") from the CES-D (yes/no).<sup>22</sup>

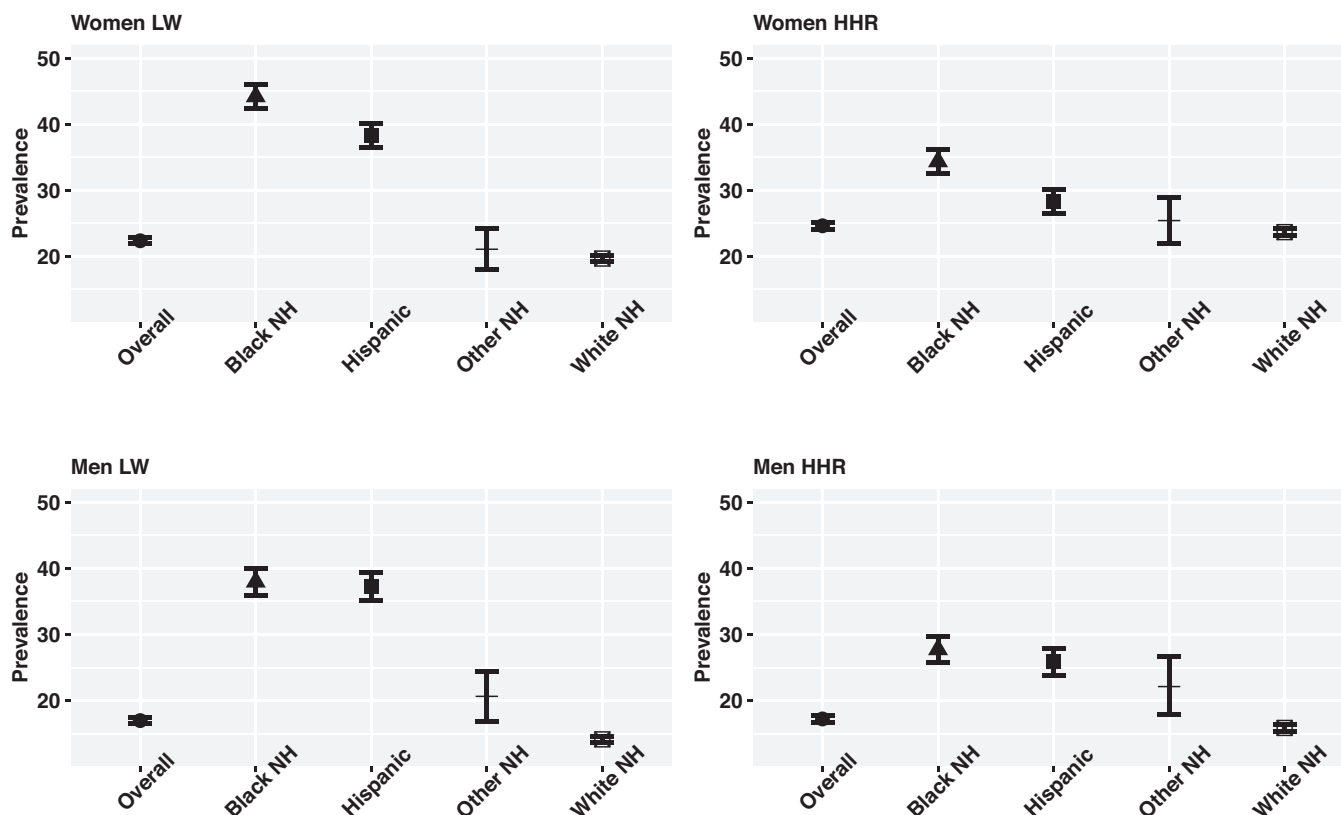
## 2.3 | Analytic strategy

Our analysis was implemented as a repeated cross-sectional design, although individuals were able to contribute to multiple waves of data to increase the precision of our estimates. We pooled data across waves and stratified by sex to estimate the prevalence of co-residing with a spouse with probable CI or dementia. We additionally calculated descriptive statistics for respondents co-residing with a spouse or partner with CI or dementia stratified by sex, by sex and race and ethnicity, and by sex and respondent age.

We next evaluated differences in the prevalence of having a spouse with (vs. without) CI or dementia using generalized estimating equations (GEE) with a Poisson distribution and a log link; GEE was used to account for the non-independence of respondents with repeated observations across multiple waves. We estimated differences by (1) race and ethnicity, adjusting for respondent's current age and HRS study wave and (2) by level of educational attainment, adjusting for respondent's current age, HRS study wave, and race and ethnicity. All models were stratified by respondent sex given differences in dementia prevalence, longevity, and late-life marital dynamics (including typical age differences between spouses). All estimates apply HRS survey weights; for each respondent, we calculated an average weight across all waves (2000–2018) in which they are included in the analytic sample. All analyses are done in STATA v. 17.

## 3 | RESULTS

Among all adults  $\geq 50$  years, the weighted estimated prevalence of co-residing with a spouse with probable CI or dementia ranged from



**FIGURE 1** Estimated prevalence of married/partnered community-dwelling adults aged  $\geq 50$  co-residing with a spouse aged  $\geq 65$  with probable CI or dementia, by sex and by race and ethnicity, based on the LW algorithm (2000–2018) and the HHR algorithm (2000–2016). Note: All estimates have been adjusted using HRS survey weights. The weights were calculated by determining the average weight for each respondent across all waves in which they are included in the analytical sample. Source: Pooled observations of respondents in the 2000 to 2018 waves of the HRS for the LW algorithm, and pooled observations of respondents in the 2000 to 2016 waves of the HRS for the HHR algorithm. CI, cognitive impairment; HHR, Hudomet, Hurd, and Rohwedder; HRS, Health and Retirement Study; LW, Langa–Weir; NH, non-Hispanic

6.2% (using the LW algorithm) to 6.8% (using the HHR algorithm) for women and was 4.4% for men (same estimate using the LW and HHR algorithms; Table S1 in supporting information).

Among all observations of participants  $\geq 50$  years, 32% of women and 35% of men were married/partnered to an individual  $\geq 65$ . Among this married/partnered subsample, the weighted prevalence of co-residing with a spouse aged  $\geq 65$  with probable CI or dementia (vs. normal cognition) was 22.3% for women (95% confidence interval: 0.218, 0.228) and 17.0% for men (95% confidence interval: 0.165, 0.174) (Figure 1). The remainder of our results are derived from this latter analytic sample.

Prevalence estimates based on the alternative HHR dementia classification algorithm were nearly identical to estimates based on the LW algorithm (25.0%, 95% confidence interval: 0.241, 0.251 for women and 17.2%, 95% confidence interval: 0.167, 0.177 for men), although prevalence estimates by race, ethnicity and education differed from the LW estimates.

After applying population weights and using the two alternative algorithms, we estimated that in any given year across the study period, approximately 1.4 (based on the LW algorithm) to 1.5 million

women (based on the HHR algorithm) and 0.8 million men (based on both algorithms) lived with a spouse with probable CI or dementia (Table 1).

### 3.1 | Estimated prevalence of having a spouse with probable CI or dementia by race and ethnicity and educational attainment

Married/partnered Black women and men had more than double the prevalence of having a spouse with probable CI or dementia compared to married/partnered White respondents (prevalence ratio [PR]: 2.37, 95% confidence interval: 2.18, 2.59 for women and PR: 2.76, 95% confidence interval: 2.47, 3.08 for men). Married/partnered Hispanic women had almost double the prevalence (PR: 1.92, 95% confidence interval: 1.73, 2.13), while Hispanic men had nearly three times the prevalence (PR: 2.66, 95% confidence interval: 2.34, 3.01) of having a spouse with probable CI or dementia compared to their White counterparts (Table 2 and Figure 2). Estimates with the HHR algorithm were of smaller magnitude, suggesting that married/partnered Black

**TABLE 1** Estimated number of community-dwelling adults aged  $\geq 50$  co-residing with a spouse aged  $\geq 65$  by spousal probable cognitive impairment/dementia status in any given year between 2000 and 2018 for the LW algorithm and in any given year between 2000 and 2016 for the HHR algorithm.

	LW		HHR	
	Spouse with probable CI/dementia	Spouse with normal cognition	Spouse with probable CI/dementia	Spouse with normal cognition
	Women		Women	
Overall	1,427,690	4,962,435	1,535,639	4,703,037
Black NH	160,236	202,391	123,223	235,463
Hispanic	166,541	268,188	116,709	295,231
Race not specified, NH	31,023	116,310	35,627	104,627
White NH	1,069,891	4,375,546	1,260,080	4,067,717
	Men		Men	
Overall	853,819	4,176,378	839,937	4,037,710
Black NH	102,144	166,819	72,587	188,975
Hispanic	117,342	198,045	76,763	219,558
Race not specified, NH	18,996	73,019	19,466	68,540
White NH	615,337	3,738,495	671,120	3,560,637

Note: All estimates have been adjusted using HRS survey weights. The weights were calculated by determining the average weight for each respondent across all waves in which they are included in the analytical sample.

Abbreviations: CI, cognitive impairment; HHR, Hudomiet, Hurd, and Rohwedder; HRS, Health and Retirement Study; LW, Langa-Weir; NH, non-Hispanic.

Source: Pooled observations of respondents in the 2000 to 2018 waves of the HRS ( $N = 30,649$  women and  $N = 24,769$  men) for the LW algorithm, and pooled observations of respondents in the 2000 to 2016 waves of the HRS ( $N = 28,284$  women and  $N = 22,769$  men) for the HHR algorithm. Both analytic samples were restricted to individuals who were aged  $\geq 50$  and lived with a spouse who was aged  $\geq 65$ .

**TABLE 2** Estimated prevalence ratios and 95% confidence intervals evaluating inequities in the prevalence of co-residing with a spouse aged  $\geq 65$  with probable cognitive impairment or dementia, by sex and race and ethnicity (compared to White non-Hispanic respondents), based on the Langa-Weir algorithm (2000–2018) and the Hudomiet, Hurd, and Rohwedder algorithm (2000–2016). Analytic sample limited to married/partnered respondents.

	LW		HHR	
	Prevalence ratio	95% CI	Prevalence ratio	95% CI
	Women		Women	
White NH, ref				
Black NH	2.37	2.18–2.59	1.51	1.36–1.69
Hispanic	1.92	1.73–2.13	1.02	0.88–1.18
Race not specified, NH	1.30	1.02–1.65	1.30	1.04–1.62
	Men		Men	
White NH, ref				
Black NH	2.76	2.47–3.08	1.71	1.50–1.96
Hispanic	2.66	2.34–3.01	1.51	1.27–1.80
Race not specified, NH	1.62	1.17–2.24	1.38	0.97–1.94

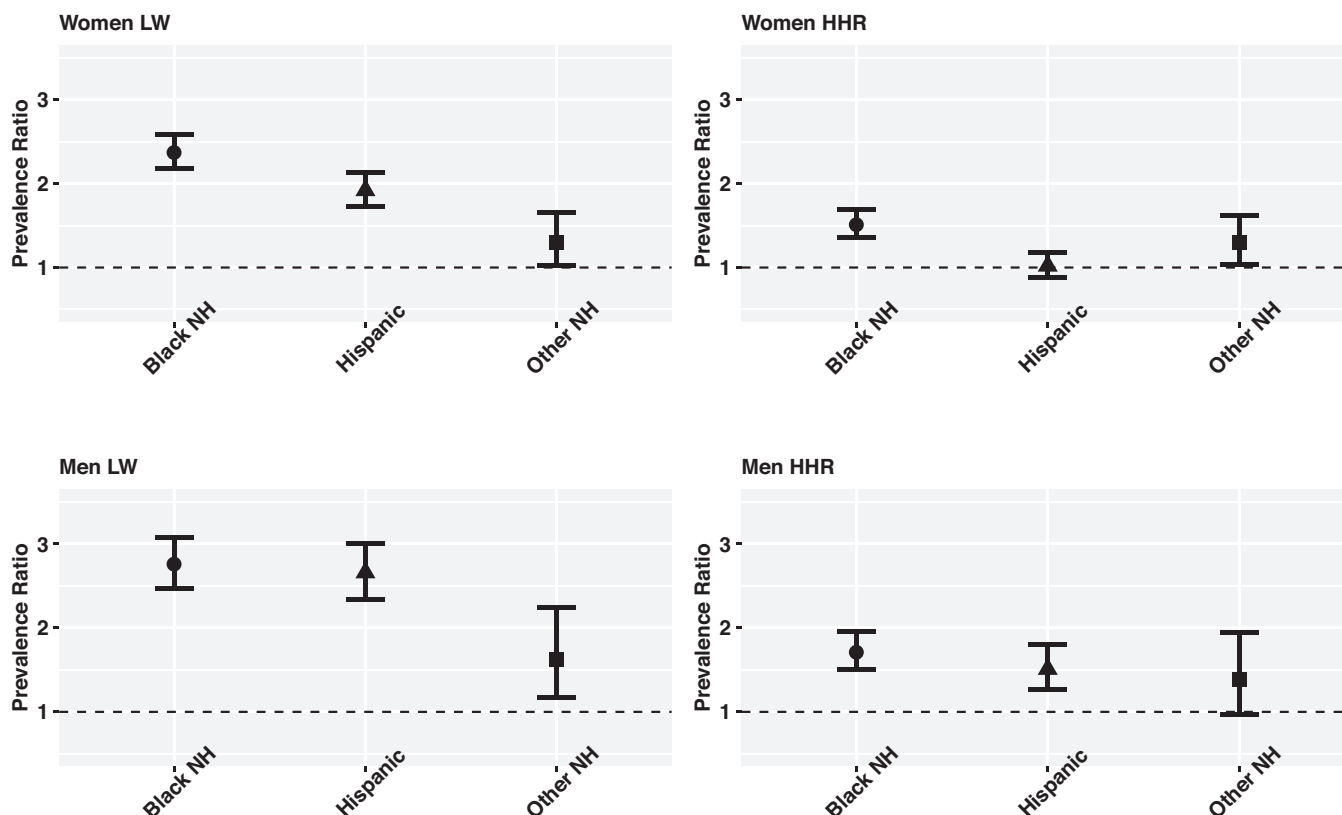
Note: All estimates have been adjusted using HRS survey weights. The weights were calculated by determining the average weight for each respondent across all waves in which they are included in the analytical sample. Controls include respondent's current age and HRS study wave.

Abbreviations: CI, confidence interval; HHR, Hudomiet, Hurd, and Rohwedder; HRS, Health and Retirement Study; LW, Langa-Weir; NH, non-Hispanic.

Source: Pooled observations of respondents in the 2000 to 2018 waves of the HRS ( $N = 30,649$  women and  $N = 24,769$  men) for the LW algorithm, and pooled observations of respondents in the 2000 to 2016 waves of the HRS ( $N = 28,284$  women and  $N = 22,769$  men) for the HHR algorithm.

women (PR: 1.51, 95% confidence interval: 1.36, 1.69), Black men (PR: 1.71, 95% confidence interval: 1.50, 1.96), and Hispanic men (PR: 1.51, 95% confidence interval: 1.27, 1.80) had a 50% to 70% greater prevalence of co-residing with a spouse with probable CI or dementia

compared to their married/partnered White counterparts. Estimates for Hispanic women (vs. White women) with the HHW algorithm were null (PR: 1.02, 95% confidence interval: 0.88, 1.18; Table 2 and Figure 2).



**FIGURE 2** Estimated prevalence ratios and 95% confidence intervals evaluating inequities in the prevalence of having a spouse aged  $\geq 65$  with probable CI or dementia among married/partnered respondents, by sex and race and ethnicity (compared to White non-Hispanic respondents) based on the LW algorithm (2000–2018) and the HHR algorithm (2000–2016). Note: All estimates have been adjusted using HRS survey weights. The weights were calculated by determining the average weight for each respondent across all waves in which they are included in the analytical sample. Controls include respondent's current age and HRS study wave. Source: Pooled observations of respondents in the 2000 to 2018 waves of the HRS for the LW algorithm, and pooled observations of respondents in the 2000 to 2016 waves of the HRS for the HHR algorithm. CI, cognitive impairment; HHR, Hudomiet, Hurd, and Rohwedder; HRS, Health and Retirement Study; LW, Langa–Weir; NH, non-Hispanic

We also observed differences in the risk of having a spouse with CI or dementia by level of educational attainment. Married/partnered respondents who completed high school or passed a General Educational Development (GED) Test (PR: 0.74, 95% confidence interval: 0.68, 0.80 for women; PR: 0.72, 95% confidence interval: 0.65, 0.80), as well as those with some college (PR: 0.54, 95% confidence interval: 0.49, 0.60 for women; PR: 0.56, 95% confidence interval: 0.48, 0.64) or a college degree or more (PR: 0.34, 95% confidence interval: 0.30, 0.39 for women; PR: 0.37, 95% confidence interval: 0.32, 0.43) were significantly less likely to live with a spouse with probable CI or dementia compared to those with less than high school education (Table 3 and Figure 3). In models that alternatively used a continuous measure of years of educational attainment, each year of additional schooling was associated with a 10% lower prevalence of co-residing with a spouse with probable CI or dementia for women (PR: 0.90, 95% confidence interval: 0.89, 0.91), and an 8% lower prevalence for men (PR: 0.92, 95% confidence interval: 0.90, 0.93; Table S2 in supporting information). Estimates with the HHR algorithm were of smaller magnitude although the general patterns were similar.

### 3.2 | Descriptive characteristics: individuals who are the spouses of people with probable CI or dementia by respondent sex

We next focus on describing the characteristics of those who co-resided with a spouse with probable CI or dementia. Weighted descriptive characteristics suggest that women who co-resided with a spouse with probable CI or dementia were an average of 72 years of age ( $\pm 8.1$  standard deviation [SD]); 22% and 17% reported ADL or IADL disability, respectively; and 28% had been hospitalized in the 2 years prior to the interview. In addition, 12% of women reported elevated depressive symptoms and 15% reported experiencing loneliness. Men who co-resided with a spouse with probable CI or dementia had a mean age of 77 years ( $\pm 7.9$  SD); 22% and 30% of these men reported ADL or IADL disability, respectively; one-third (34%) had been hospitalized in the 2 years prior; 7% reported elevated depressive symptoms; and 10% reported feeling lonely (Table 4). The descriptive characteristics of the overall sample (i.e., from which prevalence estimates were derived) are presented in Table S3 in supporting information.



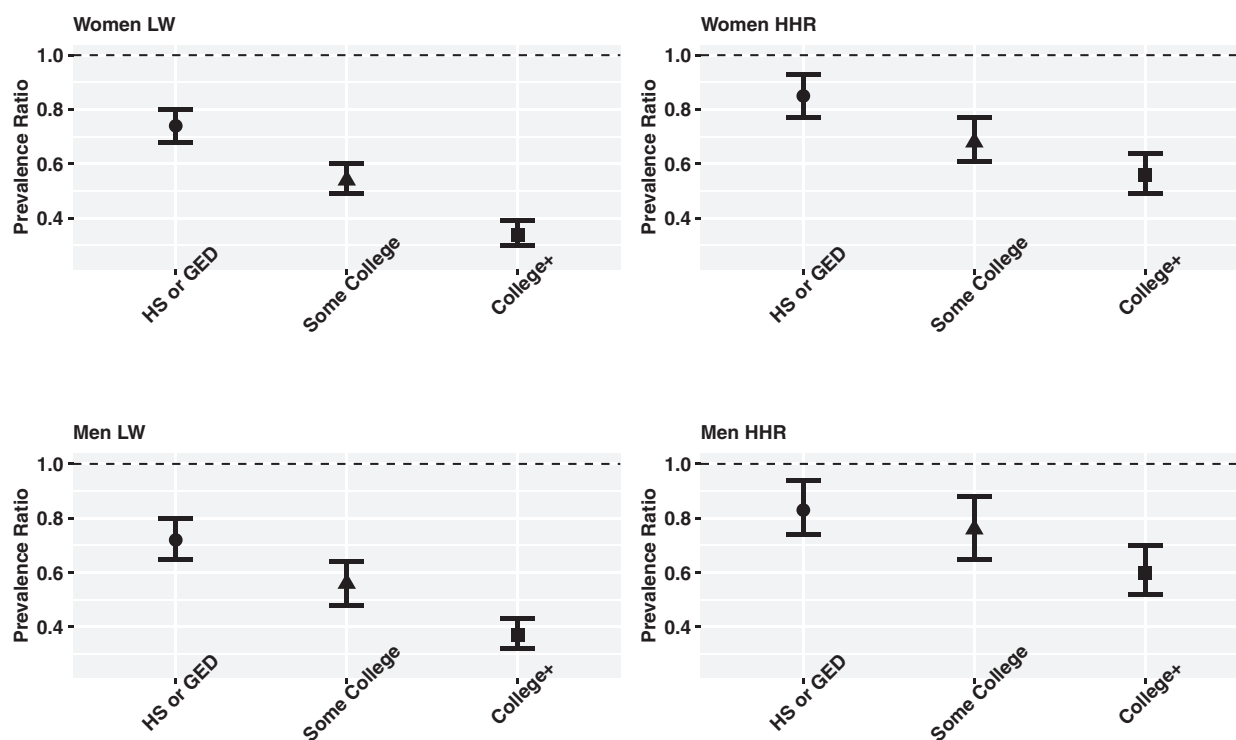
**TABLE 3** Estimated prevalence ratios and 95% confidence intervals evaluating inequities in the prevalence of co-residing with a spouse aged  $\geq 65$  with probable cognitive impairment or dementia, by sex and educational attainment (compared to respondents with less than high school), based on the Langa–Weir algorithm (2000–2018) and the Hudomiet, Hurd, and Rohwedder algorithm (2000–2016). Analytic sample limited to married/partnered respondents.

	LW		HHR	
	Prevalence ratio	95% CI	Prevalence ratio	95% CI
<b>Women</b>				
Less than high school, ref				
High school or GED	0.74	0.68–0.80	0.85	0.77–0.93
Some college	0.54	0.49–0.60	0.68	0.61–0.77
College+	0.34	0.30–0.39	0.56	0.49–0.64
<b>Men</b>				
Less than high school, ref				
High school or GED	0.72	0.65–0.80	0.83	0.74–0.94
Some college	0.56	0.48–0.64	0.76	0.65–0.88
College+	0.37	0.32–0.43	0.60	0.52–0.70

Note: All estimates have been adjusted using HRS survey weights. The weights were calculated by determining the average weight for each respondent across all waves in which they are included in the analytical sample. Controls include respondent's current age and HRS study wave.

Abbreviations: CI, confidence interval; GED, General Educational Development Test; HHR, Hudomiet, Hurd, and Rohwedder; HRS, Health and Retirement Study; LW, Langa–Weir; NH, non-Hispanic.

Source: Pooled observations of respondents in the 2000 to 2018 waves of the HRS ( $N = 30,649$  women and  $N = 24,769$  men) for the LW algorithm, and pooled observations of respondents in the 2000 to 2016 waves of the HRS ( $N = 28,284$  women and  $N = 22,769$  men) for the HHR algorithm.



**FIGURE 3** Estimated prevalence ratios and 95% confidence intervals evaluating inequities in the prevalence of having a spouse aged  $\geq 65$  with probable CI or dementia among married/partnered respondents, by sex and educational attainment (compared to respondents with less than high school), based on the LW algorithm (2000–2018) and the HHR algorithm (2000–2016). Note: All estimates have been adjusted using HRS survey weights. The weights were calculated by determining the average weight for each respondent across all waves in which they are included in the analytical sample. Controls include respondent's current age and HRS study wave. Source: Pooled observations of respondents in the 2000 to 2018 waves of the HRS ( $N = 30,649$  women and  $N = 24,769$  men) for the LW algorithm, and pooled observations of respondents in the 2000 to 2016 waves of the HRS ( $N = 28,284$  women and  $N = 22,769$  men) for the HHR algorithm. CI, cognitive impairment; HHR, Hudomiet, Hurd, and Rohwedder; HRS, Health and Retirement Study; LW, Langa–Weir; NH, non-Hispanic.

**TABLE 4** Weighted descriptive characteristics of adults aged  $\geq 50$  co-residing with a spouse aged  $\geq 65$  with probable cognitive impairment or dementia based on the Langa–Weir algorithm (2000–2018).

	Women	Men
<b>Socio-demographic characteristics</b>		
Age, mean (SD)	72.2 (8.1)	76.6 (7.8)
Native-born, <i>n</i> (%)	7170 (88)	4287 (85.7)
Race and ethnicity, <i>n</i> (%)		
Black NH	915 (11.2)	599 (12.0)
Hispanic	951 (11.7)	688 (13.7)
Race not specified NH	177 (2.2)	111 (2.2)
White NH	6109 (74.9)	3606 (72.1)
<b>Educational attainment, <i>n</i> (%)</b>		
Less than high school	11.7 (3.1)	11.1 (2.2)
High school or GED	2171 (26.6)	1806 (36.1)
Some college	3579 (43.9)	1671 (33.4)
College degree	1564 (19.2)	744 (14.9)
College degree	839 (10.3)	782 (15.6)
Total number of children, mean (SD)	3.7 (2.2)	3.6 (2.2)
Household size, mean (SD)	2.5 (1.0)	2.4 (1.0)
Homeowners, <i>n</i> (%)	6983 (85.7)	4182 (83.6)
<b>Employment characteristics, <i>n</i> (%)</b>		
Works full time	621 (7.6)	361 (7.2)
Works part time	265 (3.3)	69 (1.4)
Unemployed	68 (0.8)	48 (1.0)
Partially retired	525 (6.4)	397 (7.9)
Retired	5242 (64.3)	4057 (81.1)
Disabled	148 (1.8)	44 (0.9)
Not in the labor force	1283 (15.7)	27 (0.5)
<b>Select health characteristics</b>		
<i>Activities of daily living (ADL)</i>		
1+ limitations, <i>n</i> (%)	1765 (21.7)	1079 (21.6)
Number of limitations (range: 0–6), mean (SD)	0.5 (1.5)	0.5 (1.2)
<i>Instrumental activities of daily living (IADL)</i>		
1+ limitations, <i>n</i> (%)	1445 (17.7)	1036 (20.7)
Number of limitations (range: 0–5), mean (SD)	0.4 (0.9)	0.5 (1.1)
<b>Hospitalizations</b>		
1+ hospitalization, past 2 years, <i>n</i> (%)	2299 (28.2)	1684 (33.7)
Number of hospitalizations, mean (SD)	0.5 (1.2)	0.6 (1.5)
<i>Mental health, <i>n</i> (%) (non-proxy respondents)</i>		
Depression	949 (12.1)	323 (7.3)
Loneliness	1185 (15.1)	458 (10.3)

*Note:* All estimates have been adjusted using HRS survey weights. The weights were calculated by determining the average weight for each respondent across all waves in which they are included in the analytical sample.

Abbreviations: GED, General Educational Development Test; HHR, Hudomet, Hurd, and Rohwedder; HRS, Health and Retirement Study; LW, Langa–Weir; NH, non-Hispanic; SD, standard deviation.

*Source:* Pooled observations of respondents in the 2000 to 2018 waves of the HRS (*N* = 8152 women and *N* = 5003 men).



The descriptive characteristics of those co-residing with a spouse with probable CI/dementia varied substantially by race and ethnicity and sex (Table S4 in supporting information). For example, Black and Hispanic women co-residing with a spouse with dementia were about 3 years younger than their White counterparts. Approximately 29% of Black and Hispanic women reported ADL disability compared to 20% of their White counterparts. Similarly, the prevalence of elevated depressive symptoms was 21% for Hispanic women and 13% for Black women co-residing with a spouse with probable CI or dementia compared to 10% for their White counterparts. Black and Hispanic men were similarly about 3 years younger than their White counterparts. The prevalence of ADL disability was higher for Black (24.7%) and Hispanic (26.9%) men compared to White men (20.3%). The prevalence of elevated depressive symptoms was higher for Hispanic men (10.8%) compared to Black (7.6%) and White (6.7%) men. Other descriptive differences by race, ethnicity, and sex are in Table S4.

Unsurprisingly, descriptive characteristics also varied substantially by age (Table S5 in supporting information). For example, the estimated prevalence of ADL disability was higher for adults  $\geq 80$  years (31.6% for women and 26.6% for men) compared to their younger counterparts (e.g., 21.2% for women and 15% for men 50–64 years). However, the estimated prevalence of elevated depressive symptoms was higher for younger respondents (e.g., 14.8% for women 50–64 years compared to 9.9% for women  $\geq 80$  years). In addition, a high percentage of younger respondents—26.5% of women and 41.9% of men—reported working full-time.

## 4 | DISCUSSION

In this descriptive population-based study of community-dwelling adults  $\geq 50$  years in the United States, we provided the first estimates of the prevalence of individuals co-residing with a spouse with probable CI or dementia and documented substantial inequities by race/ethnicity and educational attainment for men and women. Specifically, we estimated that 22% of women and 17% of men who were married or partnered and living in the community co-resided with a spouse with probable CI or dementia. The prevalence for all adults  $\geq 50$  years (regardless of marital status) was an estimated 6% for women and 4% for men. Among those who were married or partnered, we further estimated that Black and Hispanic older adults were more likely to live with a spouse with probable CI or dementia compared to their White counterparts, although the magnitude of difference varied by dementia algorithm. We also found that those with higher levels of educational attainment had a lower prevalence of co-residing with a spouse with probable CI or dementia.

Our findings demonstrate the large group of older adults co-residing with a spouse with probable CI or dementia and document the substantial health and social needs of this population. Our findings also suggest that those co-residing with a spouse with probable CI or dementia are disproportionately Black and Hispanic, which likely reflects large and pervasive inequities in the burden of dementia among minoritized individuals in the United States.<sup>6–12</sup> The dispro-

portionate burden of dementia experienced by Black and Hispanic individuals has been described as an outcome of the harms of historical and contemporary racism, which shapes a wide range of life course determinants of dementia, including educational opportunities, environmental exposures, experiences of discrimination at multiple levels (e.g., institutional, interpersonal), and more.<sup>10,23,24</sup> Our findings are also influenced by trends in late-life co-residence and long-term care patterns. Black and Hispanic older adults, including those with probable CI or dementia, are much more likely to remain living at home through the end of life. This pattern partially reflects structural barriers to high-quality long-term care.<sup>17,25</sup> Increased likelihood of living in the community through the end of life among Black and Hispanic individuals may also reflect protective factors such as the greater availability of intergenerational support among Black and Hispanic families (e.g., via a higher prevalence of co-residence with adult children or other family members<sup>14,26</sup>).

We similarly found substantial inequities in the prevalence of co-residing with a spouse with probable CI or dementia by educational attainment, with a gradient reflecting the highest risk for those without a high school education and the lowest for those who were college graduates. These patterns may reflect substantial educational inequities in dementia burden,<sup>11</sup> as well as patterns of long-term care (e.g., nursing home) access and use for individuals with dementia, although evidence on socio-economic differences in nursing home use in the United States is mixed.<sup>15,17</sup> Older adults with lower levels of educational attainment are more likely to have co-residing adult children compared to their more educated counterparts.<sup>14</sup> The availability of other family members may support continued residence in the community, which would increase the prevalence of co-residing with a spouse with dementia. On the other hand, other studies have reported that those with lower levels of educational attainment are more likely to reside in nursing homes than their more highly educated counterparts.<sup>15</sup> Finally, although we did not directly evaluate heterogeneity (i.e., with multiplicative interaction terms in pooled models), models stratified by gender suggested a higher prevalence of co-residing with a spouse with CI or dementia among women. Women are on average married to older spouses as evidenced in our descriptive data, which may translate to a greater burden of spousal dementia compared to men, who tend to have younger partners.

We observed similar overall prevalence estimates when using an alternative dementia classification algorithm to the more commonly used LW method. However, this newer algorithm yielded prevalence estimates and estimates of inequity by race, ethnicity, and educational attainment that were of smaller magnitude. This finding was to be expected: recent efforts to revisit the classification of CI and dementia among HRS participants have calibrated their algorithms to specific subgroups (i.e., by race, ethnicity, and education) and have suggested that prior efforts that ignored subgroup-specific classifications may have led to overestimates of dementia prevalence for Black and Hispanic HRS participants and those with lower levels of educational attainment. Despite the important efforts to tailor dementia classification, definitive adjudication across these algorithms is challenging. The validation study on which all available algorithms are based is a

two decades old study of a subset of HRS participants with very small numbers of Black and Hispanic respondents; efforts at more sophisticated modeling have been hindered by the vanishingly small number of minoritized older adults who were included. We therefore offer these alternative estimates to reflect a potential range given the available data but encourage these estimates to be updated as soon as algorithms based on updated and more diverse validation studies are available for the core HRS.

Our study also provides a comprehensive description of demographic and health characteristics of individuals who are co-residing with a spouse or partner with dementia. While studies have reported that the majority of those who are co-resident spouses of people with dementia provide some amount of caregiving, a non-trivial percentage may not be able to provide care.<sup>27</sup> Our descriptive findings suggest that the spouses of those with dementia face substantial health challenges of their own that may limit their ability to provide care, including high rates of ADL disability and recent hospitalization. These challenges were most acute for racially and ethnically minoritized individuals who, despite being about 3 years younger than their White counterparts, had a greater prevalence of ADL disability and elevated depressive symptoms. Many of these health challenges were also pronounced for the oldest subset of respondents. However, the descriptive findings suggest that younger respondents face a higher prevalence of depression than their older counterparts and report high rates of full-time work, which may result in substantial stress in combination with co-residing with a spouse who has probable CI or dementia.<sup>28</sup> Maintaining full-time work may be critical, however, given the high cost of dementia (e.g., due to out-of-pocket costs and lost potential earnings).<sup>29</sup>

Our study is not without limitations. First, the limited number of respondents with same-sex partners within the available studies means that we could not assess the potentially unique dynamics faced by gay and lesbian older adults and their spouses.<sup>30</sup> HRS similarly does not support research on Asian American or Native American older adults because of the small sample size. This is important to address in future work given evidence of a greater burden of Alzheimer's disease and related dementias, lifetime discrimination, and structural barriers potentially faced by each of these groups in the context of adverse health.<sup>31–33</sup> Although we considered Black, Hispanic, and White men and women, each of these categories subsumes substantial diversity, which may be relevant to the likelihood of co-residing with a spouse with CI or dementia. Second, we acknowledge that respondents' own racial and ethnic identities and educational backgrounds may not correspond to their partner's, despite evidence of marital homogamy across socio-demographic characteristics at the population level.<sup>34–36</sup> Future research may further explore heterogeneity for respondents in interracial partnerships and/or with discordant socio-economic backgrounds. Third, our study focuses on individuals who are co-residing with their spouses with CI or dementia, excluding those whose partners are in nursing homes or assisted living facilities; this group might be the focus of future research in datasets that are better powered to fully characterize this group (including potential intersectional inequities). Finally, our estimates do not account for early-onset dementia (<65 years). Although early-onset dementia is rare, spouses of people with

early-onset dementia very likely experience distinctive burdens and stressors.

## 5 | CONCLUSION

There is a large and longstanding body of research on the characteristics and outcomes of spousal dementia caregivers, but a comprehensive understanding of the entire population of middle-aged and older adults impacted by spousal dementia has been extremely limited. Studies focused on spousal caregivers likely exclude individuals who are not yet providing care for their partner (e.g., during the early stages of a partner's CI) or cannot provide care due to their own physical limitations and/or CI. We found that approximately one in five community-dwelling middle-aged and older adults with a spouse  $\geq 65$  years are co-residing with a partner who has probable CI or dementia and that many of these individuals face their own health concerns, including ADL disability. We further identified stark racial, ethnic, and educational inequities in the prevalence of co-residing with a spouse or partner with CI or dementia, the magnitude of which mirrors or exceeds inequities in dementia prevalence. These findings are a critical starting point for understanding the full—and inequitable—burden of spousal mild CI and dementia in the United States. They also highlight the need for targeted resources and supports for this group of older adults to maintain their health and well-being as their spouse's condition progresses.

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## CONFLICT OF INTEREST STATEMENT

Dr. Ashwin Kotwal reports grants from Humana Inc. and receives personal consulting fees from Papa Health outside of the submitted research. Dr. Tanisha Hill-Jarrett receives personal consulting fees from Cogstate. All others have no conflicts to disclose. Author disclosures are available in the [supporting information](#).

## CONSENT STATEMENT

This is a secondary analysis of publicly available data and obtaining informed consent for this specific study was not necessary.

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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