Sexuality and Cognitive Status: A U.S. Nationally Representative Study of Home-Dwelling Older Adults

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OBJECTIVES: To determine patterns and prevalence of sexual behavior, problems, and attitudes in individuals with different cognitive status.

DESIGN: We used data from the National Social Life, Health, and Aging Project to describe the relationship between sexual behavior, function, and cognitive status (normal, mild cognitive impairment, dementia), classified using an adapted Montreal Cognitive Assessment (MoCA) (0–30 points).

SETTING: U.S. home-dwelling older adults.

PARTICIPANTS: Nationally representative probability sample of 3,196 adults (1,682 women, 1,514 men) aged 62 to 91 (mean 72).

MEASUREMENTS: Cognitive status and sexual activity, problems, and attitudes.

RESULTS: The weighted response rate was 74%. Mean MoCA score was 22.7. Of partnered people with dementia, 59% of men and 51% of women were sexually active, including 41% of those aged 80 to 91; 46% of all men (95% confidence interval (CI)=37.8–53.2%) and 18% of all women (95% CI=13.6–21.5%) with dementia were sexually active. The rate of sexual function problems was high across gender and cognitive groups (77%). Having sex primarily out of obligation was similar across cognitive groups for women (12%) and higher in men with dementia (17%) than other men (2–5%; P <.001). The majority of people were having sex less often than they would like. Few men (17%) or women (1%) with dementia talked with a doctor about sex.

CONCLUSION: Many home-dwelling men and women with dementia are sexually active. Although the rate of sexual function problems was uniformly high, people with lower cognitive function infrequently discussed sex with a physician. **J Am Geriatr Soc 66:1902–1910, 2018.**

Key words: sexuality; dementia; cognitive function; home-dwelling older adults

Until 2007, with publication of the first national study of sexuality of home-dwelling older adults in the United States,[1] knowledge about later-life sexuality was largely derived from observations of institutionalized persons with dementia.[2,3] The number of home-dwelling people with Alzheimer's disease (AD) is expected to grow from 3.2 million today to more than 8 million in 2050.[4,5] Older adults with cognitive impairment and their partners or caregivers asked physicians to help manage sexual problems and determine capacity to consent to sexual activity,[6] yet very little is known about the sexuality of home-dwelling people with dementia.

We previously showed that most people in the home-dwelling U.S. population aged 57 to 85 years have a spouse or other intimate partner and that most of those with a partner are sexually active.[1] In our study and other recent population-based cohort studies in Europe, later-life sexual activity has been found to be associated with better physical and mental health, higher quality of life, lower rates of loneliness and, in English men, better performance on some aspects of cognitive function testing.[7,8] In a Dutch cohort aged 58 to 98, satisfaction with and importance of sexual life were positively associated with better cognitive function.[9]

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Limited data on sexual behavior of people diagnosed with dementia are derived primarily from clinical and institution-based studies that are small and single site and rely on convenience samples.[10–13] Psychosocial decline, including role changes,[14] loss of recognition of the partner or memory of last sexual event,[15] difficulty with sequencing of behaviors,[16] diminished sexual interest,[11] and disability related to dementia may interfere with sexual function. In a cross-sectional study of 49 spouses of people with AD, 61% of husbands and 31% of wives found sexual activity to be important to the relationship.[11] In a similar study of 162 spousal caregivers, 28% had initiated intercourse with their spouse in the past month. Female spousal caregivers reporting sexual satisfaction experienced fewer symptoms of stress and depression.[13]

Generalizable evidence is needed to overcome biases and inform medical professionals, legal advocates, policymakers, and the public regarding sexual norms in older adults with cognitive impairment.[6] The National Social Life, Health and Aging Project (NSHAP) was designed to provide a detailed understanding of sexual behavior and function in relation to health and illness in later life. This study analyzes data from the most current, complete publicly available wave of the NSHAP survey, which assessed cognitive function using a clinically relevant measure. These data were analyzed for this manuscript between August 2017 and January 2018.

METHODS

Study Design and Population

Previously described,[1,17] NSHAP is a nationally representative, population-based, longitudinal study of health and aging using a U.S. household sample of home-dwelling adults born between 1920 and 1947. People who identify as Black or Hispanic, men, and individuals aged 75 to 84 at the time of screening were oversampled. NSHAP Wave 2 (W2, 2010–11) included spouses and cohabiting partners of Wave 1 (W1, 2005–06) respondents.[18] This secondary analysis was conducted at the University of Chicago under an institutional review board–exempt protocol. All respondents provided written documentation of informed consent and received monetary incentive for their participation.[19]

W2 data collection consisted of a home computer-assisted personal interview (CAPI) (English or Spanish) and a leave-behind questionnaire (LBQ) that respondents were to complete and mail back. The conditional response rate was 89%. Mean item-level missingness was 1% for most CAPI domains and 5% for the LBQ.[18]

We used data from 3,196 NSHAP W2 survey respondents aged 62 to 91 (1,514 men, 1,682 women). Some analyses were restricted to a subsample of partnered men (n=1,283) and women (n=1,023).

Measures

Cognitive function

After extensive pilot and validity testing,[20] an 18-item survey adaptation of the Montreal Cognitive Assessment[21] (MoCA-SA) was created for NSHAP W2.[22] MoCA-SA assessed orientation, executive function, visuospatial skills, memory, attention, and language. MoCA-SA scores (range 0–20) were transformed into MoCA scores (range 0–30) using the following validated equation: MoCA = (1.14 × MoCA-SA) + 6.83.[22] As done previously,[23] MoCA scores classified respondents as follows: normal aging (>22 points), mild cognitive impairment (MCI) (18–22), and dementia (<18).[24] We use the terms "normal," "MCI," and "dementia" to refer to the groups screening positive for these conditions. NSHAP W2 excluded individuals lacking cognitive capacity to provide informed consent or complete the interview; it is likely that the dementia group consisted of people with early dementia.

Partnership and Sexuality Variables

Partnership is defined as being married; cohabiting; or having a romantic, intimate, or sexual partner. Sex was defined according to the response to the statement: "By sex or sexual activity, we mean any mutually voluntary activity with another person that involves sexual contact, whether or not intercourse or orgasm occurs." Those who had had sex with at least 1 partner in the last 12 months were considered sexually active.

Sexual activity and behavior were assessed using questions about frequency of sex, vaginal intercourse, partner touching genitals, receiving oral sex, and masturbation in the last 12 months.

Sexual problems present for "several months or more" over the past 12 months were assessed using dichotomous response items designed for comparability with clinical criteria for sexual dysfunction[25] and NSHAP W1.[1] Respondents with 1 or more problems rated the degree to which it was bothersome (extremely, very, moderately, slightly, not at all).

Attitudes about sexuality, obligatory sex, sexual satisfaction, relationship quality (physical, emotional), and appeal of various types of physical touching were ascertained using Likert-type scales.

Other Measures

Gender was obtained according to interviewer observation and, if unclear, self-report. Age was obtained according to respondent-reported date of birth. Race, ethnicity, educational attainment, and partnership status were obtained according to self-report using close-coded questions. Race and ethnicity were assessed in the NSHAP study because of an interest in studying health disparities. Physical and mental health were assessed according to self-report using a standard 5-point scale. Depression symptoms were assessed using the 11-item Center for Epidemiologic Studies Depression (CES-D) short index.[26] A score of 9 or greater was considered indicative of a clinically significant level of depressive symptoms.[27] Respondents also reported on difficulty (no difficulty, some difficulty, much difficulty, unable to do) performing 7 activities of daily living (ADLs).

Statistical Analyses

All analyses were conducted using Stata version 15 (Stata Corp., College Station, TX), weighted to account for differential probability of selection and differential nonresponse

Table 1. Characteristics of National Social Life, Health, and Aging Project Wave 2 Survey Respondents According to Cognitive Status

Characteristic	Normal			Mild Cognitive Impairment			Dementia		
	Men, n = 814	Women, n = 938	Total, n = 1,752	Men, n = 436	Women, n = 429	Total, n = 865	Men, n = 264	Women, n = 315	Total, n = 579
	% (95% Confidence Interval)								
Age									
62–69	66.5 (59.9–73.1)	75.3 (71.1–79.6)	71.1 (67.3–74.9)	26.1 (19.3–32.9)	16.6 (13.5–19.8)	21.2 (17.8–24.6)	7.4 (4.5–10.2)	8.0 (5.4–10.7)	7.7 (5.4–10.0)
70–79	57.8 (53.3–62.2)	59.2 (54.3–64.1)	58.5 (55.1–61.9)	27.4 (23.0–31.8)	25.5 (20.8–30.1)	26.4 (23.6–29.2)	14.8 (11.7–17.9)	15.3 (11.9–18.8)	15.1 (12.8–17.4)
80–91	38.3 (31.8–44.8)	37.2 (31.4–43.1)	37.7 (32.8–42.6)	32.1 (27.5–36.6)	31.9 (26.4–37.4)	32.0 (27.7–36.2)	29.6 (23.0–36.2)	30.9 (25.3–36.5)	30.3 (25.4–35.3)
Race or ethnicity[1]									
White	63.8 (60.1–67.6)	68.4 (65.5–71.3)	66.3 (64.0–68.5)	26.3 (22.6–30.0)	20.2 (17.1–23.2)	23.1 (21.0–25.2)	9.9 (7.9–11.9)	11.4 (9.3–13.5)	10.7 (9.1–12.3)
Black	34.1 (23.5–44.8)	26.6 (20.6–32.5)	30.0 (23.2–36.9)	32.1 (26.2–38.0)	34.6 (29.8–39.3)	33.5 (29.7–37.2)	33.8 (24.3–43.2)	38.9 (33.7–44.0)	36.5 (31.4–41.6)
Non-black Hispanic	25.6 (16.4–34.8)	28.0 (18.4–37.6)	26.8 (19.5–34.1)	38.1 (26.5–49.6)	35.5 (24.4–46.7)	36.8 (28.0–45.6)	36.3 (22.2–50.4)	36.5 (23.7–49.4)	36.4 (23.7–49.2)
Other	46.0 (22.6–69.5)	53.7 (33.1–74.2)	49.4 (32.3–66.5)	30.6 (11.3–49.9)	39.9 (15.2–64.6)	34.7 (15.4–54.1)	23.4 (0.0–47.5)	6.4 (0.0–14.9)	15.8 (0.0–32.4)
Education									
<High-school graduate	20.5 (14.1–26.9)	23.0 (14.3–31.6)	21.8 (16.6–27.0)	36.0 (27.7–44.2)	29.1 (23.4–34.8)	32.4 (27.7–37.0)	43.5 (34.2–52.9)	48.0 (39.5–56.5)	45.9 (39.1–52.6)
High-school graduate	48.5 (41.4–55.7)	59.8 (53.4–66.2)	55.1 (50.1–60.0)	36.3 (29.1–43.5)	25.0 (19.4–30.6)	29.8 (24.7–34.8)	15.2 (10.1–20.2)	15.2 (11.5–18.8)	15.2 (12.2–18.2)
Some college or associate's	62.3 (57.1–67.5)	68.8 (64.1–73.4)	66.1 (62.1–70.1)	29.1 (24.6–33.6)	23.4 (19.3–27.6)	25.8 (22.5–29.1)	8.6 (5.9–11.3)	7.8 (5.3–10.3)	8.1 (6.1–10.1)
≥Bachelor's degree	79.0 (73.7–84.4)	82.4 (76.9–87.9)	80.3 (77.0–83.7)	16.8 (11.7–22.0)	14.4 (9.6–19.3)	15.9 (12.7–19.1)	4.1 (2.3–6.0)	3.2 (0.6–5.8)	3.8 (2.4–5.2)
Marital status									
Married	60.7 (56.8–64.5)	69.3 (65.4–73.3)	64.4 (61.4–67.3)	27.0 (22.9–31.0)	21.7 (18.1–25.2)	24.7 (22.0–27.4)	12.4 (9.4–15.3)	9.0 (6.5–11.5)	10.9 (8.5–13.3)
Living with partner	43.5 (27.7–59.3)	67.5 (50.8–84.2)	56.5 (43.4–69.5)	42.5 (26.4–58.7)	16.4 (3.4–29.4)	28.4 (18.0–38.8)	14.0 (0.0–29.1)	16.1 (2.4–29.9)	15.1 (2.3–28.0)
Separated or divorced	57.9 (45.1–70.7)	59.8 (51.5–68.0)	59.0 (51.7–66.3)	26.5 (15.1–37.9)	24.0 (17.7–30.3)	25.0 (19.4–30.6)	15.7 (7.6–23.7)	16.2 (10.4–22.0)	16.0 (11.7–20.3)
Widowed	41.9 (32.9–50.8)	50.3 (44.5–56.2)	48.3 (42.8–53.7)	32.3 (24.7–40.0)	24.7 (20.2–29.3)	26.6 (22.3–30.8)	25.8 (17.5–34.1)	25.0 (20.5–29.4)	25.2 (20.6–29.7)
Never married	64.1 (45.1–83.2)	46.4 (31.6–61.2)	53.8 (41.5–66.1)	19.0 (5.2–32.9)	29.8 (15.6–44.1)	25.3 (14.0–36.6)	16.8 (2.8–30.8)	23.8 (13.3–34.3)	20.9 (11.8–29.9)
Spouse or romantic or intimate partner									
No	46.6 (40.5–52.7)	52.2 (47.7–56.7)	50.7 (47.1–54.4)	29.3 (22.9–35.7)	24.6 (21.1–28.0)	25.8 (22.7–28.9)	24.1 (17.2–30.9)	23.2 (19.7–26.8)	23.5 (19.8–27.1)
Yes	60.3 (56.7–64.0)	68.6 (64.8–72.5)	63.9 (61.0–66.8)	27.4 (23.9–30.9)	21.8 (18.5–25.1)	25.0 (22.7–27.3)	12.3 (9.5–15.1)	9.5 (7.1–12.0)	11.1 (8.9–13.4)
Self-rated physical health									
Poor or fair	42.3 (36.8–47.9)	45.7 (38.4–53.1)	44.1 (38.5–49.6)	32.0 (25.5–38.5)	23.0 (18.3–27.7)	27.4 (22.9–31.9)	25.7 (19.1–32.2)	31.3 (24.7–37.9)	28.5 (23.1–34.0)
Good	58.7 (52.7–64.6)	56.9 (51.5–62.4)	57.7 (53.9–61.6)	28.7 (24.1–33.2)	27.8 (22.9–32.7)	28.2 (24.9–31.5)	12.7 (9.1–16.3)	15.3 (11.9–18.6)	14.1 (11.6–16.5)
Very good or excellent	66.6 (62.1–71.0)	74.3 (70.2–78.3)	70.5 (67.7–73.4)	24.6 (20.0–29.2)	19.4 (15.6–23.2)	21.9 (19.4–24.4)	8.8 (6.2–11.5)	6.3 (4.3–8.4)	7.6 (5.6–9.5)
Self-rated mental health									
Poor or fair	45.4 (36.4–54.4)	42.0 (35.0–49.0)	43.4 (38.1–48.8)	28.2 (20.2–36.2)	25.7 (19.5–31.9)	26.8 (21.5–32.1)	26.4 (17.8–35.0)	32.3 (23.7–40.8)	29.7 (23.9–35.6)
Good	44.2 (38.1–50.3)	55.7 (50.3–61.2)	50.5 (47.0–53.9)	34.7 (27.1–42.3)	25.5 (21.2–29.7)	29.7 (25.8–33.6)	21.1 (16.4–25.8)	18.8 (14.7–22.9)	19.9 (16.6–23.1)
Very good or excellent	67.0 (63.5–70.6)	69.1 (65.2–72.9)	68.0 (65.4–70.7)	24.2 (21.1–27.3)	21.0 (17.8–24.3)	22.6 (20.6–24.7)	8.8 (6.2–11.3)	9.9 (7.4–12.4)	9.3 (7.1–11.6)
Depression symptoms									
Yes	41.3 (33.5–49.0)	51.2 (44.9–57.5)	47.4 (42.2–52.6)	31.7 (25.0–38.3)	22.8 (18.5–27.0)	26.2 (22.4–30.0)	27.1 (19.0–35.1)	26.0 (20.9–31.1)	26.4 (22.1–30.8)
No	61.0 (57.1–64.8)	64.4 (60.8–68.0)	62.7 (60.0–65.4)	27.0 (23.2–30.8)	23.1 (20.0–26.2)	25.0 (22.7–27.4)	12.0 (9.6–14.4)	12.5 (9.8–15.3)	12.3 (10.0–14.6)

Table 1 (Contd.)

Characteristic	Normal			Mild Cognitive Impairment			Dementia		
	Men, n = 814	Women, n = 938	Total, n = 1,752	Men, n = 436	Women, n = 429	Total, n = 865	Men, n = 264	Women, n = 315	Total, n = 579
	% (95% Confidence Interval)								
Number of activity of daily living problems									
≥1	47.3 (41.9–52.7)	52.2 (47.0–57.5)	50.2 (46.2–54.1)	29.5 (23.0–36.0)	23.9 (20.4–27.4)	26.3 (22.5–30.0)	23.2 (17.7–28.8)	23.8 (19.5–28.1)	23.6 (19.8–27.4)
0	62.5 (58.8–66.1)	67.0 (63.4–70.6)	64.7 (61.9–67.6)	27.0 (23.8–30.2)	22.4 (19.3–25.6)	24.7 (22.7–26.7)	10.6 (7.9–13.2)	10.6 (7.8–13.4)	10.6 (8.4–12.7)

Estimates are weighted to account for different probabilities of selection and different nonresponse. The confidence interval is based on the inversion of Wald tests constructed using design-based standard errors.

[1]Determined based on answers to the questions: "Do you consider yourself primarily white or Caucasian, Black or African American, American Indian, Asian, or something else?" and "Do you consider yourself Hispanic or Latino?"

and stratified according to gender. Cognitive groups were compared according to demographic characteristics, self-reported physical and mental health, depressive symptoms, and physical function (based on having at least some difficulty with ≥1 ADLs). Prevalence rates of sexual behavior, problems, attitudes, and communication were determined for each cognitive status group. Approximate 95% Wald confidence intervals (CIs) for all percentage estimates were constructed, with no adjustment for multiple comparisons.

Logistic regression was used to examine the relationship between cognition categories (reference normal) and the binary sexuality outcomes, including age as a covariate, conducted separately for men and women. A separate model was fit to each outcome. To facilitate interpretation, coefficients were exponentiated to yield odds ratios, reported together with corresponding 95% CIs. An overall p-value is reported based on a 1 degree of freedom linear trend test (based on a model treating MoCA score as a continuous variable).

RESULTS

Table 1 summarizes respondents' demographic and health characteristics, stratified according to gender and cognitive status.[20] These characteristics closely match those of respondents in the 2010 American Community Survey.[28] Prevalence estimates of MCI and dementia were similar in men and women and were consistently higher in older respondents and those with less education, who were widowed or never married, and who identified as black or Hispanic. People with any cognitive impairment were 1.5 to 2.0 times as likely as those with normal cognition to report poor or fair physical or mental health, depressive symptoms, and 1 or more ADL limitations.

Overall, 83% of men and 57% of women were partnered; two couples interviewed were in same-sex relationships. The likelihood of partnership was lower with lower cognition and for women than men (Figure 1A). The overall partnership rate was higher for men with dementia (72%) than women without cognitive impairment (63%) and nearly double that of women with dementia (35%).

The likelihood of partnered sexual activity also declined with lower cognitive scores for men and women (Figure 1B) (age-adjusted odds ratio (aOR) of sexual activity = 0.61, 95% CI=0.40–0.91 for men; aOR=0.47, 95% CI=0.33–0.66 for women with dementia vs normal cognition; Table 2). Forty-six percent of men (95% CI=37.8–53.2%) and 18% of women (95% CI=13.6–21.5%) with dementia were sexually active. Of partnered people with dementia, 59% of men and 51% of women were sexually active. More than 40% of partnered men and women aged 80 to 91 with dementia were sexually active (Figure 1C). Rates of masturbation declined with lower cognitive function and were lower in women than men (Figure 1D). Overall, one-quarter of men and 10% of women with dementia reported masturbating (Table 2).

Among sexually active people, the frequency of sexual activity was similar across cognitive groups, controlling for age. Three-quarters of sexually active people, regardless of cognitive status, usually or always engaged in vaginal intercourse (Table 2). Rates of receiving oral sex were similar for men and women and trended downward with lower cognitive function. Across all cognitive groups, the majority

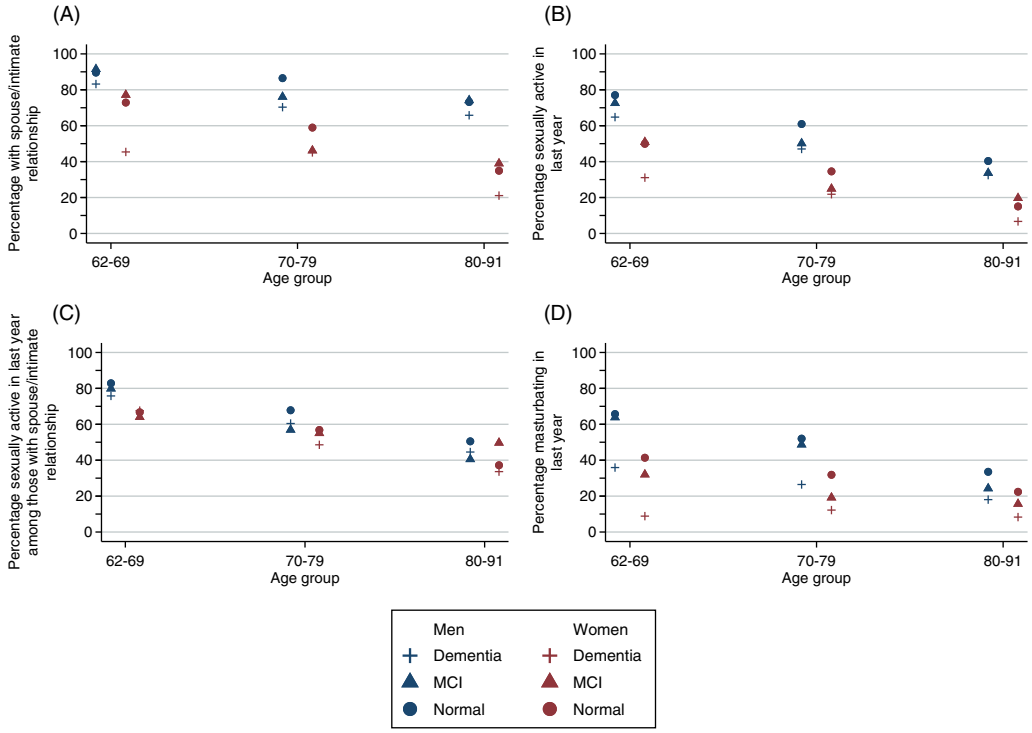

Figure 1. Prevalence of partnership, sexual activity, and masturbation according to age and cognitive status. (A) Percentage of older adults in spousal or other intimate relationship. (B) Percentage of older adults sexually active in past year. (C) Percentage of older adults sexually active in past year of those in spousal or other intimate relationship. (D) Percentage of older adults who reported masturbating in past year. Blue symbols denote men; red symbols denote women. Plus signs represent those who screened positive for dementia, triangles those who screened positive for mild cognitive impairment (MCI), and circles those who were cognitively normal.

of sexually active people reported that they usually or always felt sexually aroused during sexual activity, but people with dementia were more likely than others to engage in sexual activity without feeling aroused.

Table 3 lists the prevalence of sexual problems according to gender and cognitive status. Approximately three-quarters of men and women in all cognitive groups reported at least 1 sexual function problem; 37% of men and 12% of women with dementia had one or more bothersome sexual problems. Lack of interest in sex was similar across cognitive groups, but consistently higher in women (60%) than men (34%). Arousal difficulties in men (difficulty achieving or maintaining an erection) and women (difficulty with lubrication) were lower in those with dementia. These findings remained statistically significant for men (p=.02) but not women (p=.29) when the analyses were restricted to sexually active individuals. Inability to experience orgasm was prevalent and similar across all cognitive groups (32%), as was premature ejaculation in men (20%). Across cognitive groups, men were more likely than women to discuss sexual topics with a partner or a doctor (Table 3). The age-adjusted likelihood of talking about sexual function problems was significantly lower for men and women with dementia than for those with normal cognition. Only 1% of women with dementia spoke to a physician about sex life changes that result from a medical condition, compared with 17% of men (Supplementary Figure S1).

Overall, the majority of women and men, across cognitive groups, expressed positive attitudes about sex; 80% of men and 53% of women felt that sex was at least a somewhat important part of life, and 60% of men and 65% of women felt satisfied with the quality of their sex life. The majority of partnered people across gender and cognitive groups were satisfied with the physical and emotional quality of their sex life, although men with dementia were less likely than other men to be satisfied (Table 4). The majority of people, with little variation according to gender or cognitive status, reported that they were having sex less often than they would like. Many men and women across cognitive groups endorsed that sexual touching, light touching, cuddling, and hugging were appealing, but there was a consistent downward trend in this attitude across worse cognitive groups for men and women. Sexual touching appealed to 27% of women with dementia, 57% of women with normal cognition, and 55% of men with dementia.

Eleven percent of men and 12% of women living with a partner reported that they felt threatened or frightened by their partner. Men with dementia were several times as likely as other men to report having sex primarily out of obligation or duty (17%, vs 5% with MCI and 2% with normal cognition, aOR=10.7, 95% CI=4.0–28.4) (Table 4). For women, the rate of obligatory sex was similar across cognitive groups (12%).

DISCUSSION

This is the first study to establish nationally representative evidence about sexuality in relation to cognitive function for home-dwelling older adults in the United States. We found that, although age-adjusted rates of individual and partnered sexual activity are lower in those with worse cognitive

Table 2. Sexual Activity and Behaviors According to Cognitive Status

Sexual Activity and Behaviors	n	Normal	MCI	Dementia	MCI vs Normal	Dementia vs Normal	P-Value
		% (95% CI)			Age-Adjusted Odds Ratio (95% CI)		
Sexual activity with partner[1]							
In previous 12 months							
Men	1,450	66.7 (62.9–70.6)	55.7 (48.5–62.8)	45.5 (37.8–53.2)	0.72 (0.54–0.96)	0.61 (0.40–0.91)	.001
Women	1,625	40.1 (35.3–45.0)	31.5 (26.1–36.9)	17.6 (13.6–21.5)	0.90 (0.66–1.22)	0.47 (0.33–0.66)	<.001
≥2–3 times per month[2]							
Men	799	61.1 (57.1–65.1)	60.0 (46.2–73.9)	59.2 (45.6–72.8)	1.00 (0.55–1.80)	1.05 (0.62–1.78)	.97
Women	543	65.1 (59.5–70.7)	51.9 (40.2–63.5)	57.4 (43.7–71.2)	0.62 (0.34–1.14)	0.86 (0.46–1.58)	.43
Sexual behavior							
Vaginal intercourse usually or always[3]							
Men	803	79.4 (74.3–84.5)	77.9 (69.9–86.0)	75.1 (67.5–82.8)	0.96 (0.57–1.60)	0.90 (0.48–1.69)	.67
Women	577	75.9 (71.3–80.5)	76.0 (68.3–83.8)	76.5 (64.3–88.7)	1.11 (0.64–1.92)	1.19 (0.62–2.29)	.76
Partner usually or always touches genitals[3]							
Men	796	73.9 (70.2–77.5)	66.0 (56.4–75.6)	41.0 (31.0–50.9)	0.71 (0.47–1.08)	0.27 (0.18–0.42)	<.001
Women	569	75.8 (70.3–81.3)	68.2 (59.1–77.3)	43.5 (28.7–58.2)	0.72 (0.41–1.24)	0.27 (0.14–0.51)	.004
Oral sex received usually or always[3]							
Men	782	15.7 (12.4–18.9)	23.0 (8.9–37.1)	6.9 (1.0–12.8)	1.79 (0.76–4.21)	0.50 (0.19–1.36)	.57
Women	572	14.1 (10.7–17.5)	9.7 (3.6–15.9)	6.5 (0.0–14.4)	0.77 (0.39–1.55)	0.56 (0.15–2.08)	.10
Masturbation in previous 12 months[4]							
Men	1,357	56.8 (51.2–62.4)	49.0 (41.5–56.5)	25.3 (18.3–32.4)	0.84 (0.60–1.18)	0.35 (0.23–0.54)	<.001
Women	1,500	35.8 (31.8–39.7)	22.1 (17.3–26.8)	9.8 (5.4–14.3)	0.59 (0.43–0.81)	0.25 (0.15–0.42)	<.001
Feel sexually aroused during sexual activity usually or always[3]							
Men	829	95.2 (92.9–97.6)	91.4 (87.4–95.4)	76.7 (67.2–86.2)	0.55 (0.27–1.12)	0.18 (0.09–0.38)	<.001
Women	579	79.0 (74.1–84.0)	75.1 (67.2–83.0)	54.2 (39.4–69.0)	0.86 (0.46–1.59)	0.35 (0.17–0.72)	.13

[1]Any mutually voluntary activity with another person that involves sexual contact, whether or not intercourse or orgasm occurs. Partner defined as spouse; cohabiting partner; or romantic, intimate, or sexual partner.

[2]Question asked of respondents with current or recent (past 5 years) partner who had been sexually active in previous 12 months.

[3]Questions about these activities or behaviors were asked of partnered respondents who reported having sex in previous 12 months; questions referred to the preceding 12-month period. Vaginal intercourse was defined as how often sexual activities included vaginal intercourse (man's penis inside woman's vagina). This item was not asked of same-sex partners (2 of 955 partner dyads were same sex). Genitals touched by partner was defined as how often your partner touched your genitals with his or her hands during sexual activity. Feeling sexually aroused was defined as feeling sexually aroused ("turned on") during sexual activity with a partner.

[4]This question was asked of all respondents, regardless of partnership status. Masturbation was defined as stimulation of the genitals for sexual pleasure not with a sexual partner.

MCI = mild cognitive impairment; CI = confidence interval.

function, the majority of partnered older men and women who screen positive for dementia are sexually active, including 40% of partnered people aged 80 to 91 years. One-quarter of men and one in 10 women in the dementia group reported masturbating. Most people, including men and women with lower cognition, regarded sexuality as an important part of life and reported having sex less often than they would like.

To our knowledge, this study provides the first population estimates of sexual function problems in older home-dwelling people with lower cognition. More than one-third of men and one in 10 women in the dementia group reported bothersome sexual problems, especially lack of interest in sex. Other than controversial use of anti-gonadotropin regimens and other sexuality-suppressing pharmacological and behavioral strategies,[29] drugs and devices to treat sexual dysfunction have not been studied for use in, but may reasonably be requested by, people with dementia or their partners. Erection difficulties were lower in men with worse cognitive function, including men who were not sexually active with a partner. This finding may relate to central disinhibitory effects or other physiological mechanisms of dementia[30] or medications commonly used in this population and warrants further investigation.

One in 10 partnered people felt threatened or frightened by a partner, a factor troubling for elder abuse.[31] This worrisome rate was similar in various gender and cognitive groups and in the range of estimates of abuse and neglect reported in the 2008 National Elder Mistreatment Study.[32] In contrast, although most sexually active people across groups were satisfied with their sex life, people with dementia were more likely than others to report obligatory sex and sex without feeling aroused and to find physical touching unappealing. The finding that people with lower cognition, especially women, were also less likely to talk with a partner or a physician about sexual issues may partly explain these results. NSHAP did not directly query, and therefore we cannot estimate, the prevalence of sexual assault or rape by a partner in this population. People with more severe cognitive impairment are at higher risk of sexual victimization, a concern that has driven restrictive policies and even legal action against spouses of people with dementia.[33] Experts and guidelines call on physicians to screen for elder abuse, including sexual abuse,[34] but definitions of abuse and standards of consent to sex vary widely and can be difficult to operationalize in practice.[6] This study adds new evidence to inform improvement of these standards.

Table 3. Prevalence of Sexual Problems According to Cognitive Status

Sexual Problem	n	Normal	MCI	Dementia	MCI vs Normal	Dementia vs Normal	P-Value
		% (95% CI)			Age-Adjusted Odds Ratio (95% CI)		
Lack of interest in sex							
Men	1,384	33.3 (30.0–36.7)	33.0 (25.4–40.7)	40.0 (33.0–47.1)	0.91 (0.62–1.35)	1.09 (0.75–1.58)	.39
Women	1,503	58.7 (55.3–62.2)	59.9 (53.0–66.8)	64.5 (55.8- 73.1)	0.93 (0.66–1.29)	1.04 (0.71–1.52)	.81
Difficulty achieving or maintaining erection (men)	1,303	46.0 (42.0–50.0)	43.8 (36.2–51.3)	29.4 (22.1–36.6)	0.85 (0.59–1.23)	0.42 (0.28–0.63)	<.001
Difficulty with lubrication (women)	1,258	27.1 (22.5–31.7)	22.6 (17.7–27.5)	11.9 (6.7–17.1)	0.96 (0.67–1.38)	0.48 (0.27–0.88)	.01
Climaxing (experiencing orgasm) too quickly							
Men	1,275	21.3 (18.3–24.3)	16.8 (11.3–22.4)	21.7 (15.4–28.0)	0.79 (0.52–1.20)	1.21 (0.77–1.91)	.45
Women	1,285	3.9 (2.2–5.5)	7.7 (4.7–10.7)	3.3 (0.6–6.1)	2.62 (1.37–5.00)	1.26 (0.40–3.98)	.02
Inability to climax (experience orgasm)							
Men	1,282	31.4 (27.6–35.3)	33.9 (25.4–42.3)	33.4 (28.0–38.8)	1.06 (0.70–1.60)	0.93 (0.69–1.26)	.96
Women	1,247	34.4 (31.2–37.7)	33.0 (26.6–39.3)	24.7 (18.1–31.2)	0.98 (0.69–1.38)	0.67 (0.45–1.00)	.06
Pain during intercourse							
Men	1,328	1.9 (0.7–3.0)	1.6 (0.2–3.0)	2.6 (1.1–4.2)	0.91 (0.29–2.83)	1.71 (0.67–4.35)	.69
Women	1,336	11.4 (8.3–14.4)	9.9 (6.0–13.7)	4.6 (2.1–7.1)	1.08 (0.61–1.91)	0.55 (0.28–1.08)	.37
Sex not pleasurable							
Men	1,273	8.0 (5.9–10.1)	11.4 (4.6–18.2)	17.3 (10.9–23.8)	1.55 (0.77–3.10)	2.75 (1.54–4.90)	.002
Women	1,264	16.3 (13.3–19.2)	21.1 (15.7–26.6)	10.1 (6.6–13.7)	1.53 (0.99–2.37)	0.67 (0.43–1.05)	.94
Anxiety about ability to perform							
Men	1,291	28.5 (25.2–31.8)	25.3 (18.8–31.8)	29.3 (21.4–37.2)	0.89 (0.59–1.33)	1.17 (0.78–1.77)	.49
Women	1,316	7.2 (4.9–9.5)	7.6 (4.3–10.9)	7.7 (2.6–12.9)	1.31 (0.74–2.33)	1.50 (0.61–3.69)	.36
Had at least one sexual problem							
Men	1,335	72.9 (69.2–76.6)	74.0 (68.7–79.3)	76.6 (69.1–84.0)	1.00 (0.72–1.40)	1.07 (0.69–1.64)	.46
Women	1,416	79.9 (76.6–83.2)	78.4 (73.6–83.2)	80.5 (74.5–86.6)	0.86 (0.60–1.25)	0.95 (0.64–1.41)	.99
Bothered by sexual problems[1]							
Men	937	48.4 (44.4–52.3)	48.9 (43.0–54.8)	37.3 (29.9–44.6)	1.11(0.86–1.44)	0.74 (0.52–1.07)	.29
Women	1,022	19.6 (15.5–23.7)	14.7 (10.4–19.0)	11.6 (6.0–17.2)	0.84 (0.57–1.25)	0.77 (0.41–1.44)	.03
Avoided sex because of problems[1]							
Men	938	29.5 (23.5–35.6)	28.8 (22.9–34.8)	26.3 (16.4–36.1)	0.98 (0.65–1.46)	0.87 (0.50–1.52)	.41
Women	1,019	23.5 (18.4–28.6)	19.2 (13.2–25.3)	12.6 (6.3–19.0)	0.83 (0.51–1.37)	0.55 (0.27–1.14)	.09
Talked with partner about sexual problems[1]							
Men	818	71.5 (66.3–76.7)	70.6 (62.9–78.3)	49.4 (38.2–60.5)	1.00 (0.61–1.64)	0.42 (0.28–0.64)	.01
Women	651	64.1 (58.3–69.9)	54.4 (45.8–63.0)	41.8 (27.6–56.0)	0.69 (0.45–1.07)	0.42 (0.22–0.83)	.01
Talked with doctor about changes in sex life that may result from medical condition[2]							
Men	1,508	33.1 (27.8–38.5)	23.0 (17.5–28.5)	16.9 (12.0–21.8)	0.63 (0.42–0.94)	0.46 (0.30–0.72)	<.001
Women	1,677	11.6 (9.1–14.0)	7.1 (4.7–9.5)	1.4 (0.0–2.8)	0.73 (0.47–1.12)	0.15 (0.04–0.51)	.001

All respondents were asked about sexual problems, regardless of partnership status; questions referred to preceding 12-month period and asked about whether there had ever been a period of several months or more when the problem occurred.

[1]Questions only asked of respondents who endorsed at least 1 sexual problem. Bothersome was defined as whether sexual problem extremely, very, or moderately bothered respondent. Talking with partner about problems further restricted to those with a partner.

[2]Question asked of all respondents, regardless of partnership status.

CI = confidence interval; MCI = mild cognitive impairment.

Several limitations should be considered. Although there is little evidence to suggest that responses to sexuality questions are any less reliable than other domains, the reliability of survey responses may decline with worse cognitive function.[35] In 2 small studies of people (mostly men) with Alzheimer's disease, a minority reported a higher frequency of sex than their spouses.[12,36] The NSHAP interview methods are widely accepted as valid[1,37] and have been emulated in other large population-based studies of aging that assessed sexuality.[38,39] In most cases, NSHAP assessed gender according to interviewer observation rather than self-report, a method that could yield erroneous classification in rare cases. NSHAP did not conduct full neuropsychological testing; sorting of the sample into MCI and dementia groups according to MoCA score does not equate to diagnostic classification. The proportion of people who screened positive for dementia in our study is within range of estimates from prior studies,[40,41] and we see the expected sociodemographic, physical, and mental health associations with these conditions, all of which were also self-reported. Individuals with signs of overt dementia evident to the study interviewers were excluded, so our findings may not generalize to people with more severe dementia. Lastly, because NSHAP W2 was heavily centered on the study of marital dyads, these study findings do not yield insight into same-sex partnerships. Although measures of sexual activity were comprehensive, anal intercourse was not assessed because of high item nonresponse in the NSHAP pretest study.

We estimate that, in the home-dwelling United States population aged 62 and older, at least 1.8 million men and 1.4 million women with likely dementia are sexually active,

Table 4. Prevalence of Sexual Attitudes According to Cognitive Status

Attitude	n	Normal	MCI	Dementia	MCI vs Normal	Dementia vs Normal	P-Value
		% (95% CI)			Age-Adjusted Odds Ratio (95% CI)		
Find relationship physically pleasurable[1]							
Men	1,319	82.6 (78.9–86.2)	79.7 (74.6–84.7)	70.5 (62.7–78.3)	0.84 (0.59–1.18)	0.52 (0.34–0.79)	.03
Women	1,060	69.3 (64.8–73.7)	61.8 (52.0–71.5)	59.6 (48.1–71.1)	0.72 (0.44–1.17)	0.66 (0.39–1.12)	.25
Find relationship emotionally satisfying[1]							
Men	1,353	83.6 (80.4–86.9)	81.4 (75.5–87.3)	69.0 (59.4–78.6)	0.86 (0.57–1.30)	0.45 (0.28–0.70)	<.001
Women	1,083	69.2 (64.8–73.6)	68.3 (60.7–76.0)	62.8 (51.6–74.0)	0.95 (0.61–1.47)	0.75 (0.44–1.26)	.61
Sex at least somewhat important part of life[2]							
Men	1,256	82.3 (79.0–85.5)	79.0 (73.3–84.7)	74.4 (68.0–80.8)	0.96 (0.62–1.51)	0.99 (0.66–1.47)	.50
Women	1,400	55.8 (51.5–60.1)	52.6 (46.6–58.7)	37.5 (30.7–44.3)	1.16 (0.84–1.59)	0.67 (0.44–1.03)	.15
Think about sex once a week or more[2]							
Men	1,440	62.4 (59.1–65.7)	54.2 (48.6–59.9)	39.0 (31.3–46.7)	0.79 (0.61–1.02)	0.50 (0.37–0.70)	<.001
Women	1,596	23.3 (19.6–27.1)	15.4 (11.0–19.9)	9.3 (5.2–13.5)	0.73 (0.48–1.12)	0.45 (0.26–0.76)	<.001
Feel sex life lacking in quality[2]							
Men	1,108	39.9 (36.2–43.7)	40.8 (33.0–48.5)	39.4 (28.8–50.0)	1.00 (0.68–1.48)	0.91 (0.57–1.43)	.43
Women	990	37.0 (31.8–42.3)	33.4 (27.5–39.4)	24.6 (17.7–31.5)	0.87 (0.65–1.16)	0.56 (0.37–0.87)	.03
Had sex primarily out of obligation or duty in previous 12 months[3]							
Men	807	1.9 (0.6–3.2)	5.2 (2.2–8.3)	17.0 (8.5–25.4)	2.85 (1.14–7.12)	10.67 (4.01–28.37)	<.001
Women	638	11.5 (8.3–14.7)	10.3 (4.2–16.3)	13.7 (6.8–20.5)	1.01 (0.47–2.15)	1.60 (0.85–3.05)	.69
Felt threatened or frightened by partner[4]							
Men	1,037	9.9 (6.1–13.6)	11.7 (6.4–16.9)	12.9 (5.6–20.1)	1.27 (0.66–2.43)	1.54 (0.71–3.35)	.15
Women	862	11.9 (8.7–15.0)	12.9 (7.5–18.2)	15.0 (6.6–23.3)	1.07 (0.63–1.82)	1.32 (0.67–2.59)	.16
Appeal of physical touching[5]							
Sexual touching							
Men	1,245	81.1 (77.4–84.8)	72.4 (65.6–79.2)	54.9 (44.9–65.0)	0.69 (0.44–1.07)	0.38 (0.23–0.64)	.001
Women	1,380	56.6 (52.4–60.8)	42.7 (38.4–46.9)	26.9 (19.6–34.1)	0.74 (0.57–0.97)	0.39 (0.25–0.61)	<.001
Being touched lightly							
Men	1,285	87.6 (85.2–90.0)	85.9 (81.7–90.2)	72.4 (62.5–82.3)	0.86 (0.55–1.35)	0.37 (0.20–0.68)	.02
Women	1,443	92.3 (90.4–94.3)	84.3 (80.4–88.3)	69.0 (61.6–76.4)	0.46 (0.31–0.68)	0.19 (0.13–0.30)	<.001
Cuddling							
Men	1,271	81.3 (78.0–84.6)	74.5 (68.8–80.2)	65.0 (54.6–75.5)	0.72 (0.47–1.10)	0.51 (0.31–0.86)	.008
Women	1,431	75.5 (72.4–78.5)	64.2 (59.0–69.5)	53.5 (45.5–61.5)	0.76 (0.56–1.02)	0.52 (0.37–0.75)	<.001
Hugging							
Men	1,288	92.6 (90.3–94.9)	91.8 (87.9–95.8)	79.2 (69.2–89.2)	0.91 (0.50–1.65)	0.32 (0.17–0.60)	.02
Women	1,447	95.9 (94.3–97.6)	89.6 (86.4–92.8)	81.5 (75.9–87.1)	0.41 (0.25–0.66)	0.22 (0.12–0.41)	<.001

[1]Asked only of respondents with current or recent (past 5 years) partner. Finding relationship physically pleasurable was defined as finding relationship extremely or very physically pleasurable. Finding relationship emotionally satisfying was defined as finding relationship extremely or very emotionally satisfying.

[2]Asked of all respondents regardless of partnership status; and was asked in the leave-behind questionnaire. Feeling like sex life was lacking in quality defined as feeling it was extremely or moderately lacking in quality.

[3]Asked in the leave-behind questionnaire; those reporting that they did not have sex in the last year were excluded. Question referred to preceding 12-month period. Having sex primarily because of feeling obligated or sense of duty defined as respondents indicated feeling this way all of the time, most of the time, or more often than not.

[4]Asked in leave-behind questionnaire for those with co-resident partners.

[5]Asked of all respondents regardless of partnership status.

CI = confidence interval; MCI = mild cognitive impairment.

and this number will more than double by 2050. Physicians rarely counsel these people, especially women, about sexual changes that may result from dementia or other medical conditions. Knowledge about older-adult sexuality in the context of cognitive impairment should inform the approach to advance directives,[42] counseling, treatment, and person-centered decision-making by physicians and others charged with the ethical and humane care of older adults.

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Author Contributions: Dr. Lindau had full access to all study data and takes responsibility for the integrity of the data and the accuracy of the data analysis. Lindau, Feldmeth, Makelarski: concept and design. Dale, Feldmeth, Gavrilova, Langa, Lindau, Wroblewski: acquisition, analysis, interpretation of data. Lindau, Feldmeth, Gavrilova, Wroblewski: drafting manuscript. Dale, Feldmeth, Gavrilova, Langa, Lindau, Makelarski, Wroblewski: critical revisions of manuscript for important intellectual content. Gavrilova, Lindau, Wroblewski: statistical analysis. Dale, Feldmeth, Lindau: administrative, technical, material support. Lindau: supervision.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article.

Figure S1. Percentage of U.S. older adults who (A) have talked to their partner about their sexual function problems and (B) have had a discussion with a doctor about the changes to their sex life that may result from a medical condition, stratified according to cognitive status group, age, and sex.