

Study first to report sexual behavior norms for US adults with dementia living at home

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The majority of partnered, home-dwelling people in the U.S. with dementia are sexually active, according to a University of Chicago Medicine study out this week in the *Journal of the American Geriatrics Society*. In addition, people with cognitive impairment and dementia often have bothersome sexual function problems they don't discuss with a doctor.

"Until now, most of what we knew on this topic came from studies or legal cases involving people with advanced <u>dementia</u> living in nursing homes," said lead study author Stacy Tessler-Lindau, MD, MAPP, and UChicago Medicine professor of obstetrics/gynecology and geriatrics.

"In the next 30 years, more than 80 million people in the U.S. will be 65 or older. A growing number of people with dementia live at home, cared for by a spouse who, like doctors and society more generally, don't have the knowledge they need to manage the sexual aspects of life with a person with dementia," she said.

This study is the first to look at a nationally-representative sample of this population.

The number of home-dwelling people with Alzheimer's Disease (the most common type of dementia) is expected to grow to more than eight million by 2050.

Researchers found that of partnered people with dementia in their study,



59 percent of men and 51 percent of <u>women</u> were sexually active. More than 40 percent of partnered men and women ages 80 to 91 also reported being sexually active. But the likelihood of partnered sexual activity declined with lower cognitive scores for both women and men in the study.

"The lack of basic information about sexual behavior, function and desires in this growing population is a problem," said Lindau, "because these aspects of life with dementia raise ethical, legal, clinical and even moral questions that we as a society are largely unprepared for."

For example, posited Lindau, can a person with dementia consent to sex or be deprived of sex because we're not sure she can consent? Should a doctor treat a person with dementia for sexual dysfunction? Does a person with <u>cognitive impairment</u> have an obligation to fulfill "marital duty?"

The study's authors looked at data from more than three thousand homedwelling people in the United States between the ages of 62 and 91. In a previous study, Lindau and co-authors found later-life sexual activity to be positively associated with physical and mental health and was regarded by most men and women as an important part of life.

The majority of people, across all cognition groups in the current study, reported positive attitudes about sex and that they were having sex less often that they would like. More than one in 10 partnered men and women reported feeling threatened or frightened by their partner; this rate was not higher among people with dementia.

"Physicians may be asked to determine whether a patient with dementia has the capacity to consent to sex and have to balance the obligation to protect the patient from harm with the obligation to protect the person's autonomy," Lindau said. "We now have normative evidence that should



help counter negative bias and inform important decisions about sex for people with dementia."

More than one-third of men and one in 10 women in the study's dementia group reported bothersome sexual problems, but only 17 percent of men and one percent of women with dementia talked to a physician about sex life changes that result from a medical condition like dementia.

According to Lindau, there are a growing number of FDA-approved treatments for sexual dysfunction, and many of these are targeted to older adults.

"Sometimes the person complaining about the patient's sexual function problems is the partner, not the patient with dementia. Doctors need to be prepared for how to handle that," she said.

The study is titled "Sexuality and Cognitive Status: A U.S. Nationally Representative Study of Home-Dwelling Older Adults."

More information: Stacy Tessler Lindau et al, Sexuality and Cognitive Status: A U.S. Nationally Representative Study of Home-Dwelling Older Adults, *Journal of the American Geriatrics Society* (2018). DOI: 10.1111/jgs.15511

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