

# Study explores impact of early dementia screening of older adults on their family members

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A new grant to the Indiana University Center for Aging Research from the National Institute on Aging funds the first study to assess the potential benefits and harms to family members of early dementia screening of older adults.

The Effects on Families of older adults Experiencing Cognitive Testing (EFECT) study is linked to the Indiana University CHOICE trial, a ground-breaking randomized controlled study assessing the harms and benefits of screening for dementia, compared to no screening for dementia, among 4,000 older adults cared for in typical primary care practices.

"EFECT is the first study to investigate if the benefits for family members—who may likely evolve into caregivers—of early [dementia screening](#) of seemingly cognitively healthy older adults outweigh the harms," said IU Center for Aging Research and Regenstrief Institute scientist Nicole Fowler, Ph.D, who leads the new study. "Our results will directly inform optimal care for older adults at risk of dementia as well as impacting the lives of the spouses, daughters, sons, and other family members who face the daunting task of caring for a loved one with dementia.

"We will measure family members' knowledge of the screening event and potential caregiver preparedness in terms of the ability to plan for

future care needs and accessing community and long-term care support. We will also be able to assess if early identification of dementia by screening harms family members by inducing anxiety or depression."

Dr. Fowler, an implementation scientist with the IU Center for Health Innovation and Implementation Science—a part of the Indiana Clinical and Translational Science Institute, reported in 2012 and 2015 studies that more than half of older adults are willing to be screened for dementia in primary care.

The aims of the EFECT study include evaluating the impact of dementia screening on family members' health-related quality of life and well-being and the impact of dementia screening on family members' mood and anxiety. The researchers are also assessing the impact of dementia screening on family members' caregiving preparedness and caregiving self-efficacy.

Currently about half of patients with dementia in the U.S. are undiagnosed. It is not known whether dementia screening better prepares family members for the practical, physical, and emotional realities of caregiving or impacts their well-being and health-related quality of life.

The United States Preventive Services Task Force has stressed the need for research on links between dementia screening and patient or family caregiver outcomes given the tremendous burden of dementia on family caregivers.

There are an estimated 5.4 million adults with Alzheimer's disease or related dementias and 11 million dementia caregivers in the United States. By 2050, it is estimated that those numbers will rise to 13.8 and 27 million, respectively.

"Delaying a diagnosis of [dementia](#) has the potential to impact the family

member's behaviors toward the patient and their perceived role," said Dr. Fowler. "For example, it may perpetuate the belief that changes in cognition are part of 'normal aging' which have been shown to aggravate family caregivers' stress, burden, and sense of isolation, which, in turn, may impact the health of caregivers and their ability to access important services."

NIA has awarded \$126,000 to support EFECT in conjunction with CHOICE, which has received \$2.65 million in NIA funding through 2017.

Provided by Indiana University

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