

Predicting how Alzheimer's disease progresses

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Credit: Duke University

Alzheimer's disease is the nation's most expensive, costing an estimated



\$236 billion dollars in 2017. But for the more than 5 million people living with it, and for their loved ones, no dollar value can account for the day-to-day suffering. It's a disease that robs one in three seniors of their golden years, yet strikingly little is known about it.

An initial diagnosis almost always comes with more questions than answers. What's the cause? What are the stages? And what exactly is the <u>life expectancy</u>?

While the disease's progression generally includes three stages (mild, moderate, and severe), this linear-sounding development is often not at all the case according to SSRI Research Professor Eric Stallard. An expert in medical demography, his current work analyzes individual variation in the progression of Alzheimer's.

"The progression of the disease can vary from patient to patient," he said. "Some experience the need for full time care early and need that care for years, while others have a much shorter lifespan and die before ever reaching the need for full time care."

The result is that families don't necessarily know how to plan for their loved one as the disease progresses. For example, a 75-year old Alzheimer's patient may receive a diagnosis with a general expected life span of 6 years.

"But what those 6 years may look like," Stallard added, "or whether that 6-year value is even approximately correct, can change dramatically from patient to patient."

Many patients will eventually need full time care, and that can leave families scrambling for years while their loved one deteriorates.

"For many families, it can be a real hardship, caring for children and



caring for an aging parent at the same time, while on a limited income," Stallard said.



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It's difficult to plan for that care, especially when such little information is provided as to what to expect and when to expect it.

To give families a better picture of what happens after diagnosis, Stallard and his colleagues Yaakov Stern at Columbia University and Bruce Kinosian at the University of Pennsylvania analyzed data assembled by Stern from 229 Alzheimer's patients followed over 10



years—data now housed on SSRI's Protected Research Data Network.

Their analysis uses a new system that combines two different models, now termed the L-GoM extension of the Sullivan life table model. Their presentation at the 2016 Alzheimer's Association International Conference was the first public showing of the model and it's offering some promising insights into how Alzheimer's disease progresses.

Stallard and his collaborators modeled the progression of the disease over the course of the 10-year study to estimate total, disabled and nondisabled life expectancies for each individual Alzheimer's patient using the need for full time care as the measure of disability.

They then divided the 229 patients into five relatively homogeneous but intentionally distinct subgroups based on their initial locations in the model.

By comparing the observed and estimated survival curves for each subgroup, they were able to assess the accuracy of the model.

What they found was that the model-based estimates were substantially similar to the observed values. In fact, the estimated survival curves were almost all within the 95% confidence margins of the observed survival curves, indicating that the model could produce highly accurate life expectancy estimates for individual patients.

While their results are promising, Stallard cautioned that there are elements of randomness that could affect individual patient outcomes. Still, the model seems to offer a clearer picture than previous methods.

More than just the average six-year lifespan, this model could provide a better prognosis for families looking to their loved one's needs. The approach itself provides a powerful new tool for personalized predictive



modeling in clinical, research, and public health applications.

Provided by Duke University

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