To screen or not to screen … an ethical debate

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Over the past several months, the topic of Alzheimer's disease has been in the headlines, including the cover of *TIME*. Many of the stories have focused on the debate about expanding the number of brain images in the population.

There is nothing new in the debate regarding the value of early detection of Alzheimer's disease and other age-related dementia. There is, though, a growing awareness of the prevalence of the problem and the realization that in a rapidly aging world population, where people live longer than ever before, the pending number of individuals with these diagnoses is staggering. Cost of care for this burgeoning population is beyond the resources currently available, which is unknown in regard to the revised health care legislation passed in 2010.

In 2003, Richard J. Hodes, MD, the director of the National Institute on Aging, brought this concern directly to the Senate Committee on Appropriations. At that time, the total number of Americans diagnosed with Alzheimer's disease was 4 million, and the annual cost of care was estimated at $100 billion. Hodes spoke about the numbers rising—both people and cost of care—as baby boomers age. He also discussed the strides being made in research and the "powerful imaging techniques that target anatomical, molecular, and function processes in the brain" to identify people at high risk for developing the disease.

Seven years later, the number of Americans diagnosed with Alzheimer's is 5.3 million, and that excludes individuals diagnosed with mild cognitive impairment—a condition that results in memory problems not normal in an age group but not fitting the classification of dementia. The cost of care is currently estimated to be $172 billion annually (National Alzheimer's Association, 2010 Facts and Figures).

Imaging equipment has improved significantly since Hodes addressed the Committee, and the question posed at the 2010 International Alzheimer's Research Conference in Hawaii was "would pursuing early detection provide opportunities for delaying the progression of the disease and the associated disabilities and loss of independence in people who are at high risk or even the total population?" In other words, should early detection be mandated?

Questions about the effectiveness of early detection that came out of that discussion and several other meetings of physicians, psychiatrists, researchers, pharmaceutical CEOs, and advocates have to be resolved before any recommendation for mandatory screening could be agreed upon by all of the stakeholders, including those with the diagnosis or high-risk profile. What would early detection mean in regard to the privacy of the information and the rights of the individual being screened?

Some of the questions discussed by Stephen G. Polst, PhD, in *The Moral Challenge of Alzheimer's Disease,* Johns Hopkins Press, 2000, are:

- Diagnostic disclosure—who gets to know; who needs to know?

- Would mandatory restrictions be placed on driving?
- Would long-term care insurance and life insurance be available to presymptomatic individuals with a diagnosis?
- Would individuals be able to retain their own power of attorney and determine their advanced directives?
- Would treatment/drug trials be mandatory? Conversely, would interventions for other illnesses be denied based on the diagnosis of Alzheimer's disease?

In *Bioethics and the Brain,* Oxford University Press, 2007, author Walter Glannon, PhD, probes the concerns of experimental drugs and the unknown outcomes of exploration of the brain with imaging techniques. Since "brain replacement" is not possible, damage to the brain through experimental treatments in individuals who may never develop the symptoms of Alzheimer's disease (Snowden, The Nun's Study) is a major unanswered question.

Before funding and final decisions can be made, these questions and others need to be discussed and reviewed. The money associated with the manufacturing of imaging equipment and cost of screening could be a primary driver of a decision to mandate screening for individuals with profiles that assume high risk for Alzheimer's disease. On the other hand, I have talked with many people who have age-related dementia illnesses. Most express a need to know and want to take any action that might enhance their quality of life—both in the present and the future.

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