

CHANGING THE TRAJECTORY OF ALZHEIMER'S DISEASE:

A NATIONAL IMPERATIVE

APPENDIX A

The Alzheimer's Association report, *Changing the Trajectory of Alzheimer's Disease: A National Imperative*, presents information about the impact of Alzheimer's disease based on data from a model developed for the Alzheimer's Association by The Lewin Group. The report presents information about three alternate trajectories: 1) the current trajectory, 2) a delayed onset trajectory, and 3) a slowed progression trajectory. Appendix A describes the model and the research findings used to develop it.

The Lewin Group Model

The Lewin Group Model allows the user to project the trajectory and impact of Alzheimer's disease given various scenarios, including the current scenario, in which there are no known treatments that can change the course of the disease, and alternate scenarios, in which hypothetical treatments could become available to delay the onset and/or slow the progression of the disease. Based on data from scientific research and national surveys, the model allows the user to project the number of people who have or will have Alzheimer's disease in single years from 2000 to 2050, the number and proportion who will be in the mild, moderate or severe stage of the disease in any year during that period, and the cost of their care to all payers and to specific payers, including Medicare, Medicaid, other payers (such as, private insurance, HMOs, other managed care organizations, and uncompensated care) and out-of-pocket costs to people with Alzheimer's disease and their families.

Methodology

The Lewin Group model combines analytical techniques reported by Sloane et al. (2002)¹ for examining the potential impact of breakthrough treatments for Alzheimer's disease; incidence rates (the percent of individuals that develop Alzheimer's disease over the course of a year) reported by Evans et al. (2003)² and resulting prevalence rates (the percent of individuals who have Alzheimer's disease) reported by Hebert et al. (2003);³ estimates of stage of disease reported by Graham et al. (1997);⁴ per capita costs of care for Medicare beneficiaries age 65 and older from the 2004 Medicare Current Beneficiary Survey and Medicare claims (2009);⁵ and mortality rates and estimates of differential costs by stage of disease (mild, moderate and severe) based on a previous analysis by The Lewin Group (2004).⁶

The model begins with a national count of individuals with Alzheimer's disease, and then, using incidence rates, estimated rates of progression from mild to moderate and moderate to severe Alzheimer's disease, and differential mortality rates, projects the number of individuals with Alzheimer's disease by stage of disease for each single year to 2050.

The model projects national data and does not take into account regional, state, or local differences in incidence, prevalence, stage of disease, mortality, or costs.

Incidence and Prevalence of Alzheimer's Disease

To develop incidence and prevalence rates, the model starts with incidence rates reported by Evans et al. (2003)² and prevalence rates reported by Hebert et al. (2003).³ These rates are based on findings from the same population-based, longitudinal research study. The Hebert et al. projections of prevalence of Alzheimer's disease from 2000 to 2050 indicate a declining prevalence within age groups as a result of increased educational attainment, associated with less likelihood of developing Alzheimer's, among future cohorts of people age 65 and older. To approximate the Hebert et al. (2003) prevalence projections, the incidence rates from Evans et al. (2002) are adjusted downward over time based on the increasing proportion of people age 65 and older with a high school education.

Stage of Disease

To establish baseline figures for the proportion of people with Alzheimer's disease that are in the mild, moderate, or severe stage of the disease, the model uses findings from the Canadian Study of Health and Aging, reported by Graham et al. (1997).⁴ The Canadian study was chosen as the basis for determining these baseline figures because the comparable figures reported by Hebert et al. (2003)³ are for a sample of individuals with incident disease and therefore include a higher proportion of individuals with mild disease than would be found in a sample that also contained prevalent cases.

Progression Between Stages of Disease

The model assumes that without new treatments that could delay the onset or slow the progression of Alzheimer's disease, the transition probability from the mild to the moderate stage of the disease is 45 percent annually, and the transition probability from the moderate to the severe stage of the disease is 28 percent annually. These baseline transition probabilities were developed for a previous analysis by The Lewin Group⁶ to convert the single transition probability from Sloane et al. (2002),¹ which estimates the transition rate from the mild stage to a combined moderate/severe stage into two estimated transition probabilities that estimate the transition from the mild to the moderate stage and from the moderate to the severe stage.

Mortality Rate

The model uses age-specific mortality rates from the Social Security Administration to project the number of people age 65 and older that will die of all causes.⁷ Several studies have found higher mortality rates for individuals with Alzheimer's disease.^{8,9} Based on these study findings, the model assumes differential mortality rates of 1.2 for individuals in the mild stage of Alzheimer's disease; 1.5 for individuals in the moderate stage of the disease; and 2.0 for individuals in the severe stage.

Delayed Onset of Alzheimer's Disease

The model allows the user to delay the onset of Alzheimer's disease by 1 to 10 years from the baseline trajectory and to select the year in which this change will take effect. For this report, the Alzheimer's Association chose to delay the onset of Alzheimer's disease by five years beginning in 2015.

Slowed Progression of Alzheimer's Disease

The model allows the user to select transition probabilities from the mild to moderate stage of the disease and from the moderate to severe stage of the disease and to select the year in which these changes will take effect. For this report, the Alzheimer's Association chose to slow progression beginning in 2015, so that only 10 percent of people with Alzheimer's disease would transition from the mild to the moderate stage annually and only 5 percent would transition from the moderate to the severe stage annually.

Costs of Care

The model uses per capita costs to all payers for the care of people with and without Alzheimer's disease and costs of care to specific payers from an analysis of data from the 2004 Medicare Current Beneficiary Survey (MCBS) and Medicare claims.⁵ In the MCBS and the Medicare claims data, Medicare beneficiaries age 65 and older were identified as having Alzheimer's disease or other dementias based on responses of the beneficiary or a proxy to an MCBS question about whether a doctor had ever said the person had Alzheimer's disease or dementia and/or diagnostic codes for Alzheimer's disease and other dementias on Medicare claims for any Medicare service in 2004. The costs of all kinds of medical care, nursing home and other residential care, home and community-based services, and medications are included.

The cost of care data from the 2004 MCBS and Medicare claims are not reported by stage of disease. Thus, the model uses estimates of differential costs of care by stage of disease based on a previous analysis by The Lewin Group (2004).⁶ For that analysis, The Lewin Group estimated differential costs of care by stage of disease based on findings from Leon et al. (1998)¹⁰ and Small et al. (2002).¹¹ Both of those studies found that average costs of care increased by stage of disease. The factors that are used in the current model to determine the differential costs of care by stage of disease are as follows: mild stage = 0.79; moderate stage = 1.05; and severe stage = 1.57.

To estimate Medicaid payments for nursing home care for individuals with Alzheimer's disease, the model uses average annual Medicaid payments per user for nursing home care inflated by the rate of increase per capita among nursing home residents from The Lewin Group's Long Term Care Financing Model. The current model developed for the Alzheimer's Association assumes that per capita costs for nursing home care do not vary by stage of disease, but that the rate of institutionalization does. The change in Medicaid costs assumes that individuals with Alzheimer's disease who are in a nursing home would not be in the nursing home if they did not have Alzheimer's and would be less likely to be in a nursing home if they were in an earlier stage of the disease. These assumptions overstate the effect of delayed onset and/or slowed progression on Medicaid nursing home costs because some proportion of individuals with Alzheimer's disease in nursing homes have multiple reasons for being in a nursing home and might be there even if they did not have Alzheimer's disease.

Inflation

The model allows the user to select the baseline year for costs and to include or not include adjustments for inflation. For this report, the Alzheimer's Association selected to show costs in constant 2010 dollars. The Association chose not to increase costs over time to reflect the impact of general inflation. However, health care inflation over and above general inflation is captured in the costs shown in constant 2010 dollars in this report.

Costs for Hypothetical Treatments to Delay Onset or Slow Progression

The model allows the user to project the costs for hypothetical treatments to delay the onset or slow the progression of Alzheimer’s disease. The Alzheimer’s Association chose to not include such costs in this report because the possible treatments range so widely in cost, from a relatively low cost treatment, such as a change in diet or exercise, to a relatively high cost treatment, such as a medication or a cocktail of medications that would be taken several times a day over a long period of time.

References

- 1 Sloane, PD; Zimmerman, S; Suchindran, C; Reed, P; Wang, L; Boustani, M; et al. “The Public Health Impact of Alzheimer’s Disease, 2000-2050: Potential Implication of Treatment Advances,” *Annual Review of Public Health* 2002;23(1):213-231.
- 2 Evans, DA; Bennett, DA; Wilson, RS; Bienias, JL; Morris, MC; Scherr, PA; et al. “Incidence of Alzheimer Disease in a Biracial Urban Community: Relation to Apolipoprotein E Allele Status,” *Archives of Neurology* 2003;60:185-189.
- 3 Hebert, LE; Scherr, PA; Bienias, JL; Bennett, DA; and Evans, DA. “Alzheimer Disease in the US Population: Prevalence Estimates Using the 2000 Census,” *Archives of Neurology* 2003;60:1119-1122.
- 4 Graham, J; Rockwood K; Beattie, BL; Eastwood R; Gauthier S; Tuokko, H; et al. “Prevalence and Severity of Cognitive Impairment With and Without Dementia in an Elderly Population,” *The Lancet* 1997;349(9068):1793-1796.
- 5 Alzheimer’s Association, “Characteristics, Costs & Health Service Use for Medicare Beneficiaries with a Dementia Diagnosis,” contract report prepared for the Alzheimer’s Association by Julie Bynum, MD, MPH, Dartmouth Center for Health Policy Research, January 2009.
- 6 The Lewin Group, “Report of The Lewin Group to the Alzheimer’s Association,” in Alzheimer’s Association, *Saving Lives, Saving Money: Dividends for Americans Investing in Alzheimer Research*, 2004.
- 7 Social Security Administration, mortality rates by single year of age for the years 2000 to 2050, accessed August 21, 2009.
- 8 Dodge, HH; Shen, C; Pandav, R; DeKosky, ST; and Ganguli, M. “Functional Transitions and Active Life Expectancy Associated With Alzheimer Disease,” *Archives of Neurology* 2003;60:253-259.
- 9 Wilson, RS; Aggarwal, NT; Barnes, LL; Bienias, JL; Mendes de Leon, CF; Evans, DA. “Biracial Population Study of Mortality in Mild Cognitive Impairment and Alzheimer Disease,” *Archives of Neurology* 2009;66(6):767-772.
- 10 Leon, J; Cheng, C-K; and Neumann, PJ. “Alzheimer’s Disease Care: Costs and Potential Savings,” *Health Affairs* 1998;17(6):206-216.
- 11 Small, GW; McDonnell, DD; Brooks, RL; and Papadopoulos G. “The Impact of Symptom Severity on the Cost of Alzheimer’s Disease,” *Journal of the American Geriatrics Society* 2002;50(2):321-327.