Executive Summary

Diabetes is a common chronic disease. More than 12 percent of the American population age 65 and older have this diagnosis. The direct medical costs of treating diabetes and its complications have been estimated at $44 billion per year (in 1997 dollars) and the indirect costs associated with lost productivity have been estimated at $54 billion per year. Another cost, the quantity of time spent by informal (unpaid) caregivers providing daily assistance (diet, medications, checking blood glucose) as well as assistance needed because of the disability associated with diabetes-related complications has not been evaluated.

This Issue in Brief will describe an empirical investigation using data from the University of Michigan Asset and Health Dynamics (AHEAD) Study, a nationally representative survey of people aged 70 or older. Our aim was to determine the hours of informal caregiving and the cost of that time for elderly Americans living in the community. By determining a nationally representative estimate of informal caregiver time for diabetes and its associated cost, we hope to provide useful data for determining the full societal impact of the increasing number of elderly with diabetes, as well as the cost-effectiveness of interventions aimed at decreasing the incidence of diabetes and its complications. In addition, a better understanding of how diabetes and its complications lead to significant burden on caregivers may aid in targeting potential interventions to assist the families of the elderly with diabetes.
The Data

We used data from the baseline 1993 survey of the Asset and Health Dynamics (AHEAD) Study, a biennial longitudinal survey of 7,443 community-dwelling Americans born in 1923 or earlier. This sample is representative of the approximately 21 million community-dwelling elderly in the United States. The overall survey response rate was 80 percent.

All respondents were asked: “Do you have diabetes?” Respondents answering yes were then asked questions regarding their present treatment and grouped into four categories reflecting increasing severity of the condition: 1) No Diabetes, 2) Diabetes, taking no medication to treat diabetes, 3) Diabetes, taking oral medication only, 4) Diabetes, taking insulin.

Summary of Major Findings

Characteristics of the Study Population

- 13% of respondents reported having diabetes. Of those, 17% took no medications to treat it, 53% took oral medication only, and 30% used insulin.
- Compared to those without diabetes, those with the disease were younger, more likely to be African American, to be unmarried and living with others, and to have less wealth.
- Diabetics were more likely than non-diabetics to have heart disease, stroke, visual impairment, urinary incontinence, arthritis, and cognitive impairment. There were no differences in these two groups in rates of lung disease, cancer, and psychiatric problems.
- Diabetics taking insulin took an average of 4.6 different medications compared to 2.2 for those without diabetes.
- Diabetics were more likely than non-diabetics to report impairment in at least one significant daily activity (such as walking across the room and grocery shopping). Those with diabetes taking no medication and those taking only oral medication were in between diabetics and non-diabetics for reporting impairment.

Weekly Hours of Informal Caregiving

- Those with diabetes taking insulin received 14.4 hours per week of informal care compared to 6.1 hours per week for those without diabetes. Those with diabetes taking no medication received 10.5 and those taking oral medications only received 10.1 hours per week.
- Much of the difference between the insulin diabetic and non-diabetic group can be accounted for by higher rates of heart disease and visual impairment in the former group. When these complications were included in the analysis, the difference in number of hours of caregiving per week for insulin diabetics vs. non-diabetics dropped from 7.8 to 5.2, decreasing the difference substantially.
- Accounting for cognitive impairment and urinary incontinence did not change number of informal caregiving hours for those with diabetes, suggesting that these conditions did not account for much of the difference in caregiving hours between those with and without diabetes.
Finally, accounting for number of medications, the difference in caregiving hours between those with diabetes using insulin and those without diabetes again decreased from 5.2 hours per week to 4.0 hours.

Yearly Cost of Informal Caregiving for Diabetes

In a model that did not take into account differences in caregiving hours accounted for by diabetic complications and higher rates of other medications in diabetics, the cost of informal caregiving for those with insulin diabetes was $6,100 per year compared to $2,600 per year for those without diabetes (for a difference of $3,500). In a model that did adjust for these things, the difference in yearly cost decreases from $3,500 to $1,700 per year.

Because the sample used for these analyses is representative of all Americans aged 70 and older living in the community, we are able to multiply these costs to obtain national estimates. In the unadjusted model, the total cost for informal caregiving for elderly diabetics is approximately $6 billion per year. Adjusting for diabetic complications and higher rates of other medications in diabetics, the total cost is $3 billion.

Conclusion

The growing prevalence of diabetes combined with the growing number of elderly Americans will likely lead to a significant increase in the number of people required to provide informal care. This study showed that diabetes imposes a substantial burden on elderly individuals and their families, and society, both through increased rates of disability and the significant time that caregivers must spend helping address the limitations associated with that disability. Several important caveats must be noted. Our classification of diabetes presence and absence and medications relied entirely on respondent self-report. However, other studies have found self-report for these variables to be quite reliable. In addition, because of the limitations of the data, we did not include some important diabetic complications such as kidney disease and lower extremity amputations. Inclusion of these would clarify differences among the groups studied. Nonetheless, this population-based study of informal care for the elderly with diabetes makes clear the significant burden of this disease. The economic cost associated with informal caregiving should be considered in future analyses of both public health consequences of diabetes and interventions aimed at decreasing diabetic complications.
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