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Informal Caregiving For Diabetes and Diabetic Complications Among Elderly Americans

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Abstract

Objectives: Little is known regarding the amount of time spent by unpaid caregivers providing help to elderly individuals for disabilities associated with diabetes mellitus (DM). We sought to obtain nationally representative estimates of the time, and associated cost, of informal caregiving provided to the elderly with diabetes, and to determine the complications of DM that contribute most significantly to the subsequent need for informal care.
Methods: We estimated multivariable regression models using data from the 1993 Asset and Health Dynamics (AHEAD) Study, a nationally representative survey of people aged 70 or older (N=7,443), to determine the weekly hours of informal caregiving and imputed cost of caregiver time for community-dwelling elderly with and without a diagnosis of DM.
Results: Those without DM received an average of 6.1 hours per week of informal care, those with DM taking no medications received 10.5 hours, those with DM taking oral medications received 10.1 hours, and those with DM taking insulin received 14.4 hours of care (P<.01). Disabilities related to heart disease, stroke, and visual impairment were important predictors of diabetes-related informal care. The total cost of informal caregiving for elderly individuals with diabetes in the U.S. was between $3 and $6 billion per year, similar to prior estimates of the annual paid long-term care costs attributable to DM.
Discussion: Diabetes imposes a substantial burden on elderly individuals, their families, and society, both through increased rates of disability and the significant time that informal caregivers must spend helping address the associated functional limitations. Future evaluations of the costs of diabetes, and the cost-effectiveness of diabetes interventions, should consider the significant informal caregiving costs associated with the disease.

Authors' Acknowledgements

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Introduction

Diabetes mellitus (DM) is a common chronic disease diagnosed in about 10 million people in the United States, including more than 12 percent of the elderly population age 65 or older (Harris et al., 1998). In addition, a significant number of Americans, perhaps as many as 5 million, are believed to have undiagnosed diabetes (Harris et al., 1998). The direct medical costs associated with treating diabetes and its complications (including heart disease, stroke, visual impairment, hypertension, kidney disease, and amputations), is estimated at about $44 billion per year (in 1997 dollars) (American Diabetes Association, 1998). The "indirect costs" of diabetes, those associated with lost productivity due to morbidity and premature mortality, have been estimated at an additional $54 billion per year (American Diabetes Association, 1998).

Another cost associated with diabetes, the quantity of time spent by unpaid (informal) caregivers providing daily assistance with diabetes care (e.g., helping with diet, medications, and checking blood glucose), as well as care for diabetes-related complications (e.g., limitations in mobility due to heart failure, stroke, and lower-extremity amputations), has not been previously evaluated. One study (Silliman, Bhatti, Khan, Dukes, & Sullivan, 1996) found that family members frequently helped with daily diabetes care, as well as with instrumental activities of daily living (e.g., shopping, cleaning, and cooking), but the total amount of time provided by caregivers was not evaluated.

Identifying and accounting for this previously undocumented component of diabetes care is especially important now, as the number of elderly with diabetes in the U.S. will likely increase significantly over the next few decades due to the aging of the baby-boom generation,

increasing rates of obesity (Mokdad et al., 2000), and an increase in minority populations that exhibit higher rates of DM (Harris, Eastman, Cowie, Flegal, & Eberhardt, 1999).

Our study had three related objectives. The first was to determine the rates of disability among the U.S. elderly with diabetes. The second was to obtain generalizable estimates of the total time that family members spend providing help to address these disabilities. The third objective was to assess the relative proportion of additional caregiving for those with DM that was related to important diabetic complications (e.g., heart disease, stroke, and visual impairment) and to diabetic treatment (e.g., increased number and complexity of medications). By determining a nationally representative estimate of informal caregiver time for diabetes, 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. 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.

Conceptual Model of Informal Caregiving for Diabetes

Figure 1 presents a model for how the presence of diabetes may lead to increased levels of informal caregiving. We hypothesize that the majority of informal care for those with diabetes is provided to address disabilities in activities of daily living (ADLs—walking across a room, dressing, bathing, eating, transferring, and toileting) and instrumental activities of daily living (IADLs—cooking, grocery shopping, using the telephone, taking medications, and managing money) that result directly from diabetes (e.g., mobility limitations due to neuropathy, muscle weakness, or impaired wound healing) or as mediated through increased rates of heart disease (Fuller, 1985; Haffner, 1999), stroke (Stegmayr & Asplund, 1995; Folsom et al., 1999), visual

impairment (National Institutes of Health, 1995), cognitive impairment (Leibson et al., 1997; Gregg et al., 2000), lower extremity amputations (Humphrey et al., 1994), kidney disease (National Institutes of Health, 1995), and urinary incontinence (Nakayama, Jorgensen, Pedersen, & Raaschou, 1997). As the number of medications and the complexity of the medical regimen required to treat diabetes and its complications increases, so too will informal caregiving for medication-related help. Diabetes-specific informal care (as opposed to that provided for help with ADLs and IADLs) will include activities such as help with glucose monitoring, foot care, and adherence to a diabetic diet (Silliman et al., 1996). Help with increased transportation needs, such as to physician visits and dialysis centers, will also result in additional time spent by informal caregivers.

Elderly individuals with diabetes may also have comorbidities that are unrelated to the presence of DM, such as lung disease, cancer, arthritis, or psychiatric illness. These comorbidities may also result in informal caregiving either directly or through increased levels of functional impairment.

Other potential predictors of informal care include sociodemographic characteristics of the patient and family (e.g., age, race, gender, education, and net worth), the availability of informal care (e.g., whether the elderly person is married, unmarried and living with others, or unmarried and living alone), and health system characteristics (e.g., the availability of possible substitutes for informal care such as paid home care or nursing home services) (Stone, Cafferata, & Sangl, 1987; Kemper, 1992; Wolf, Freedman, & Soldo, 1997; Katz, Kabeto, & Langa, 2000).

Properly identifying and attributing the caregiving costs that arise from a particular disease may be difficult when, as in the case of diabetes, the disease is a risk factor for other chronic

conditions (Gold, Siegel, Russell, & Weinstein, 1996; American Diabetes Association, 1998; Kirschstein, 2000). Since individuals with diabetes are at higher risk for heart disease, stroke, and visual impairment, for example, some of the costs that arise from these complications should be attributed to diabetes. However, heart disease and stroke would likely occur in some of these individuals even if diabetes were not present, so it would be incorrect to attribute *all* costs associated with heart disease to diabetes. Another complexity in proper attribution of costs arises because the presence of diabetes might result in increased severity (and costs) for other diseases even if it is not a direct cause for the condition (e.g., impaired wound healing related to diabetes may complicate recovery from any surgical procedure). Given this inherent uncertainty regarding proper attribution of costs, we determined an upper and lower bound estimate for diabetes-related caregiving using both unadjusted and adjusted caregiving hours as described below.

Data and Methods

Data

We used data from the baseline 1993 survey of the Asset and Health Dynamics (AHEAD) Study, a biennial longitudinal survey of a nationally representative cohort of the U.S. elderly born in 1923 or earlier (Soldo, Hurd, Rodgers, & Wallace, 1997). Our analysis included all 7,443 community-dwelling elderly age 70 or older who were enrolled in the baseline survey. This sample is representative of the approximately 21 million community-dwelling elderly in the United States.

The AHEAD survey was designed to study health transitions in old age and their impact on individuals, families, and society. In addition to measures of the health and functional status of the elderly survey respondents, data are collected on the number of hours of care provided by

both paid and unpaid caregivers in the home. Most respondents age 70 to 79 (74%) were interviewed by telephone, while most of those age 80 and older (69%) were interviewed in person. The overall survey response rate was 80 percent, and response rate did not differ significantly for those interviewed by phone compared to those interviewed in person (Soldo et al., 1997).

Approximately 10 percent of respondents were unable or unwilling to complete the AHEAD survey by themselves (Soldo et al., 1997). A proxy respondent, most often a spouse (45%) or daughter (29%), completed the survey for these individuals.

Dependent Variables

A respondent was considered to have a disability in an ADL if they reported having difficulty with or receiving help for that ADL. Disability in an IADL was defined as having difficulty performing the IADL without help, or not doing an IADL because of a health problem (Norgard & Rodgers, 1997). We classified respondents as receiving informal care if in-home assistance with any ADL or IADL was provided by a relative (paid or not), or unpaid non-relative with no organizational affiliation (Norgard & Rodgers, 1997). AHEAD respondents were identified as recipients of informal care if, because of a health problem, they received *any* help with IADLs. However, due to the survey design, we were able to identify only those respondents who received help with an ADL "most of the time." So less frequent help for ADLs (that provided "some of the time" or "occasionally") could not be included in the analysis.

The intensity (number of weekly hours) of informal home care was calculated using the average number of days per week (in the prior month), and average number of hours per day that respondents reported receiving help from informal caregivers. The methodology used for

calculating weekly hours of care from the AHEAD data has been previously described (Wolf et al., 1997; Langa, Chernew, Kabeto, & Katz, 2001) Because data on hours per day of care were not collected for caregivers who helped less than once per week, we imputed weekly hours of care for these infrequent helpers using a regression model based on reported caregiver characteristics (helper sex, residential status, relationship to the respondent, and number of days per week of care) (Wolf et al., 1997). Missing caregiving hours data were imputed for a total of 19 percent of informal caregivers. Because most caregivers with missing data were those who provided very infrequent help (less than once per week), they accounted for less than 2% of the total informal caregiver hours analyzed in the study. We re-ran all analyses after dropping any observation for which data were imputed and found no significant change in our results. We imposed a limit of 16 hours of care per day for any individual caregiver to allow for 8 hours of sleep (Ernst & Hay, 1994; Penrod, Kane, Finch, & Kane, 1998). This truncation of caregiving hours affected about 6 percent of the 2,700 informal caregivers identified in the AHEAD survey.

Classification of Diabetes Mellitus Status

All respondents were asked: "Do you have diabetes?" If a respondent answered "yes," he/she was then asked the following two questions regarding present treatment for DM:

1) Are you now using medication that you swallow to treat or control your diabetes?
2) Are you now using insulin injections?

The responses to these three questions were used to sort respondents into four mutually exclusive categories (Figure 2): 1) No DM; 2) DM, taking no medications (to treat DM); 3) DM, taking oral medication only; and 4) DM, taking insulin. We hypothesized that these four categories represent, on average, respondents with increasingly severe diabetes (both in terms of average level of hyperglycemia and duration since diagnosis) (Hayward, Manning, Kaplan, Wagner, & Greenfield, 1997) and, therefore, we expected complications (heart disease, stroke, and visual

impairment), number of ADL and IADL impairments, and hours of informal caregiving to increase monotonically from category 1 to category 4.

Data needed to assign DM status were missing for five respondents who, therefore, were excluded from the analysis.

Independent Variables

The sociodemographic measures included in the analysis as independent variables were: age (70-79, 80-89, ≥90), race (white, black, other), sex, living situation (unmarried living alone, unmarried living with others, married) net worth (terciles), and years of education (<12, 12, ≥13). The self-reported chronic medical conditions included were: heart disease, stroke, visual impairment (corrected eyesight reported as "poor"), urinary incontinence, lung disease, cancer, psychiatric problem, and arthritis. Cognitive impairment consistent with dementia was defined based on poor performance on a cognitive screening test for self-respondents (Brandt, Spencer, & Folstein, 1988; Langa et al., 2000), or "fair or poor memory" as assessed by a proxy respondent. Number of prescription medications (0, 1-2, ≥3) was also included as an independent variable since we expected medication-related help to increase with the number of medications.

To determine upper and lower bounds of the additional informal caregiving attributable to DM, we estimated six different regression models that varied in the set of included independent variables. Model 1 included diabetes category as the only independent variable, so all variation in caregiving hours is effectively attributed to diabetes, thereby yielding an upper-bound estimate. To Model 1, we sequentially added independent variables that might account for some of the variation in caregiving hours across DM categories. As independent variables are added

sequentially to the regression model, their impact on caregiving hours is no longer attributed to DM, so the final model represents a lower-bound estimate of caregiving for diabetes since none of the informal caregiving associated with important diabetic complications is attributed to the presence of diabetes. Independent variables were added to the regression model in the following order: **Model 2)** sociodemographic measures and comorbidities expected to be "unrelated" to diabetes (lung disease, cancer, psychiatric problem, and arthritis); **Model 3**) heart disease and stroke ("macrovascular" complications of diabetes); **Model 4)** visual impairment (a "microvascular" complication of diabetes); **Model 5)** dementia and incontinence (conditions associated with diabetes, but causality is unclear); and **Model 6)** number of medications (a measure of treatment complexity).

Analytic Framework

Because a substantial proportion of respondents received no informal care in the month prior to the administration of the survey, and the distribution of hours among recipients was highly skewed, we analyzed caregiving using a two-part multivariable model (Duan, Manning, Morris, & Newhouse, 1983; Kemper, 1992). To determine the likelihood of receiving informal care, we first used logistic regression to estimate the association of DM with receipt of any informal care in the prior month, controlling for the other covariates included in the model. In the second part, we used ordinary least squares (OLS) regression to examine the association of DM with the natural logarithm of informal care hours per week for persons who received any care. The results from each part of the model were then combined to obtain an estimate of the average effect of DM on weekly hours of informal caregiving (Duan et al., 1983; Kemper, 1992). For ease of interpretation, regression results were re-transformed back into natural units (hours) (Manning, 1998).

Calculating the Cost of Informal Care

Opportunity cost, or the value of a resource in its next best use to society, is the preferred measure of cost for economic analyses in health care (Gold et al., 1996).The opportunity cost of an informal caregiver's time is sometimes assigned using the average hourly wage of working individuals with similar characteristics (age, gender, education), but for some groups of caregivers (the retired elderly, for instance) there are no appropriate wage data. An alternative approach is to use the market price of an equivalent service (such as a home health aide) as an estimate of the opportunity cost of a caregiver's time. Some argue, however, that this method may overstate the cost of caregiver time since, presumably, a caregiver values his/her time at less than the home health aide wage, or else a home health aide would be hired to provide the care (Gold et al., 1996). Because many caregivers in our analysis were retired, we used this latter method to estimate the yearly cost of informal caregiving for each DM category by multiplying the 1998 average national wage for a home health aide ($8.17 per hour) (Bureau of Labor Statistics, 1999) by the weekly hours of care, and then multiplying by 52 (weeks per year). We calculated both an upper- and lower-bound cost estimate for informal caregiving by using the upper-bound (Model 1) and lower-bound (Model 6) estimate of caregiving hours attributable to DM.

We tested the significance of the interaction between diabetes and each of the other chronic diseases included in the analysis in order to examine the hypothesis that the presence of diabetes is associated with increased caregiving time for other related and unrelated comorbidities. None of these interaction terms reached statistical significance, so they were not included in the final models used to determine adjusted informal caregiving hours.

All analyses were weighted and adjusted for the complex sampling design (stratification, clustering, and non-response) of the AHEAD survey (Soldo et al., 1997; STATA Reference Manual: Release 6.0, 1999). STATA Statistical Software: Release 6.0 was used for all analyses.

The AHEAD Study was approved by the institutional review board at the Institute for Social Research, University of Michigan. The data used for this analysis contained no unique identifiers so respondent anonymity was maintained.

Results

Characteristics of the Study Population

The characteristics of the study population (N=7,438) are shown in Table 1. Thirteen percent of respondents reported having diabetes. Of those with DM, 17% took no medications to treat it, 53% took oral medications only, and 30% used insulin (alone or in combination with oral medication). Compared to those without DM, those with DM (all categories) were significantly younger (P<.001) and more likely to be African-American (P<.001). Those with DM were also more likely to be unmarried and living with others, and to have low net worth (P<.001).

Diabetics were more likely than non-diabetics to report a history of heart disease (P<.001), stroke (P<.001), visual impairment (P<.001), urinary incontinence (P=.02), and arthritis (P<.001). Those with DM were also more likely to have cognitive impairment consistent with dementia (P<.001). There was no significant difference across the DM categories in reported rates of lung disease, cancer, and psychiatric problems. Number of medications was strongly associated with DM category: those taking insulin reported using an average of 4.6 medications compared to 2.2 for those without DM (P<.001). More than three-quarters of diabetics using insulin took 3 or more medications compared to only 38% of non-diabetics. Diabetics taking no (diabetes-related)

medicine and those taking oral medication only had rates of medication use that were between those of non-diabetics and diabetics using insulin.

ADL and IADL Impairments

Diabetics were significantly more likely than those without DM to report at least one ADL or IADL impairment (28% of those without DM, about 40% of diabetics taking no medications or oral medication only, and 54% of those taking insulin) (P<.001) (Table 2). The mean number of ADL and IADL impairments for those with DM taking insulin was more than twice that for those without DM (P<.001).

Table 2 also shows the specific ADL and IADL impairments associated with diabetes category. The most prevalent ADL limitation for both diabetics and non-diabetics was "walking across a room," with 22% of those without DM reporting a limitation and 46% of those with DM taking insulin reporting limitation (P<.001). The most prevalent IADL limitation was “grocery shopping” with 17% of non-diabetics and 36% of diabetics reporting a limitation (P<.001). A similar pattern was found for nearly all other ADLs and IADLs: those with DM taking insulin were about twice as likely to report a functional limitation for a given ADL/IADL compared to those without DM (P<.001). Those with DM taking no medication and those taking only oral medication had rates of functional limitation that were intermediate between those without DM and those with DM taking insulin.

Weekly Hours of Informal Caregiving

Elderly individuals with DM received significantly more weekly hours of informal caregiving than those without DM. Figure 3 shows that, prior to adjustment for any other covariates (Model 1), those without DM received a mean of 6.1 hours per week of informal care, those with DM

taking no medications received 10.5 hours, diabetics taking oral medicines received 10.1 hours, and those taking insulin received 14.4 hours (P<.01). Differences across the DM categories in sociodemographic measures and comorbidities "unrelated" to DM (Model 2) accounted for a relatively small portion of the additional caregiving received by those with diabetes, as suggested by the small changes in caregiving hours for each group after adjustment for these variables (see Figure 3). In contrast, higher rates of both macrovascular (Model 3) and microvascular (Model 4) diabetic complications did account for a significant share of the additional caregiving received by diabetics, especially among those taking insulin. After adjusting for these complications the difference in caregiving hours between the No DM group and the insulin group decreased by about one-third, from 7.8 hours to 5.2 hours. Addition of controls for dementia and incontinence (Model 5) did not significantly change informal caregiving hours for those with DM, suggesting that these conditions did not account for much of the difference in caregiving between those with and without DM, once adjustments for important macrovascular and microvascular complications were made. Finally, adjusting for the total number of medications (Model 6) further reduced the difference in caregiving between groups, most notably for those taking insulin. Adjustment for number of medications decreased the difference in caregiving hours between those without DM and those taking insulin by about one-quarter, from 5.2 to 4.0.

Yearly Cost of Informal Caregiving for Diabetes.

Table 3 shows the estimated hours per week and cost per year of the informal caregiving associated with diabetes. Using the unadjusted hours of informal caregiving for each DM category (the "upper-bound estimate") the cost of caregiving for those without DM was $2,600 per year while the cost for those with DM taking no medication was $4,500, or an *additional* cost of $1,900 per year for those with DM. There was an additional yearly cost of $1,700 for those taking oral medication and $3,500 for those taking insulin. Using the adjusted caregiving hours

from Model 6 (the "lower-bound" estimate), the additional yearly cost associated with DM was $1,000 for those taking no medication, $800 for those using oral medications, and $1,700 for those using insulin.

Given the nationally representative sample used for this analysis, an estimate of total informal caregiving costs due to DM for the community-dwelling elderly age 70 or older in the United States can be calculated. Our findings suggest there were about 460,000 community-dwelling elderly with DM who were taking no medications, 1,430,000 taking only oral medication, and 800,000 using insulin. The upper-bound estimate of additional yearly cost of informal care attributable to DM for these groups is about $870 million, $2.4 billion, and $2.8 billion, respectively, yielding a total additional yearly cost of about $6 billion per year. The analogous lower-bound estimates using the adjusted caregiving hours are $460 million, $1.1 billion, and $1.4 billion, yielding a total of about $3 billion per year for informal caregiving attributable to DM.

Discussion

The growing prevalence of diabetes, combined with the growing number of elderly Americans over the next 20 to 40 years, will likely lead to a significant increase in those who require daily help for disabilities caused by diabetes and its complications. This study of a nationally representative sample of the community-dwelling elderly in the United States shows that diabetes is associated with significantly higher rates of disability among the elderly and that family members spend a substantial amount of time providing help with both diabetes treatment (e.g., help with medications) and the functional limitations that result from diabetic complications. To our knowledge, this is the first study to quantify this significant burden and cost of unpaid caregiver time associated with diabetes and its complications.

The relative magnitude and importance of informal caregiving for diabetes can be put in perspective by comparing its cost to that of other components of diabetes care. For instance, the estimated combined cost of both nursing home and paid home health services for individuals age 65 and over with diabetes in the U.S. is about $5.4 billion per year (in 1998 dollars) (American Diabetes Association, 1998). Our estimate of between $3 and $6 billion (in 1998 dollars) for diabetes related informal caregiving suggests that the societal cost for this unpaid component of diabetes care is similar to that for paid long-term care services.

The wide-ranging impact that diabetes and its complications may have on the independent functioning of the elderly is made evident by our findings: diabetes was associated with significantly higher rates of disability for each ADL and IADL, with rates for those taking insulin nearly twice those for individuals without diabetes. Limitations due to difficulties with mobility (e.g., walking across a room or grocery shopping) were especially prevalent among those with DM, perhaps due in part to lower extremity diabetes-related complications such as peripheral vascular disease, peripheral neuropathy, myopathy, and amputations.

Our analysis suggests that increased rates of heart disease, stroke, and visual impairment were important predictors of disability that, in turn, led to about one-third of the increased informal caregiving associated with diabetes. In addition, the significantly greater number of medications used by those with diabetes was associated with a significant portion of the increased informal care received by those with diabetes. However, caution should be used when interpreting the relative importance of these factors. The significant correlation among these variables makes it difficult to disentangle the independent influence of each (Gujarati, 1988). We added variables to the regression model in an order that seemed clinically reasonable (i.e., macrovascular

complications, microvascular complications, and then medications), but changing the order in which the variables were added would change their estimated relative impact on caregiving for diabetes due to the correlation among them.

We employed methods that likely led to conservative estimates of diabetes-related informal caregiving time and cost. Most importantly, only caregiving for ADLs and IADLs is included in the analysis. Other time costs, such as those associated with help with home glucose monitoring or driving diabetic patients to physician visits and dialysis centers, are not included in the analysis. Also, the AHEAD survey does not identify infrequent help for ADLs, so this caregiving is also not included in the analysis. Finally, the hourly wage that we used as an estimate of informal care cost was lower than that used in many prior studies of the cost of informal caregiving for other diseases (Rice et al., 1993; Weinberger et al., 1993; Ostbye & Crosse, 1994; Ernst & Hay, 1994; Stommel, Collins, & Given, 1994; Max, Webber, & Fox, 1995).

A number of potential limitations of our study merit comment. First, our classification of the presence of diabetes, present medications, and comorbidities were based on respondent self-report and were not confirmed by medical records or serum glucose testing. However, self-reports of diabetes medications have been found to be quite accurate (Hayward et al., 1997), and the self-reported diabetes prevalence in the AHEAD cohort (~13%) was nearly the same as that found in the Third National Health and Nutrition Examination Survey (NHANES III), a prior population-based study (Harris et al., 1998). NHANES III estimated that an additional 6% of the U.S. elderly population have undiagnosed diabetes. To the extent that those with undiagnosed diabetes have disabilities requiring informal care, our study under-estimates the total national cost of informal care for diabetes.

We did not have data on the presence of important diabetic complications such as kidney disease, peripheral vascular disease, neuropathic disease, and lower extremity amputations. We expect that these complications were responsible for at least some of the "unexplained" difference in informal care for diabetes that we found in our full regression model (Model 6).

Finally, as with all observational studies, the possibility exists that an omitted variable (e.g. another comorbidity) that is correlated with both the presence of diabetes and informal caregiving is the "true cause" of the increased caregiving that we found for those with diabetes. However, we included important sociodemographic measures and other common comorbidities among the elderly that have previously been shown to influence the level of informal care. In addition, as discussed above, our estimate of the time and cost associated with informal caregiving for diabetes is a conservative one, so it is unlikely that we have significantly over-estimated the cost of diabetes caregiving due to an omitted variable.

This population-based analysis of informal care for the elderly with diabetes makes clear the significant burden that this increasingly prevalent condition places on elderly individuals, their families, and society. The economic cost associated with informal caregiving should be considered in future analyses of both the public health consequences of diabetes and interventions aimed at decreasing diabetic complications. Future studies should also examine how increasing rates of obesity and diabetes among younger Americans might reduce the pool of potential informal caregivers for the elderly due to early diabetic complications and subsequent disability among middle-aged adults.

Figure 1. Conceptual Model of Informal Caregiving for Diabetes

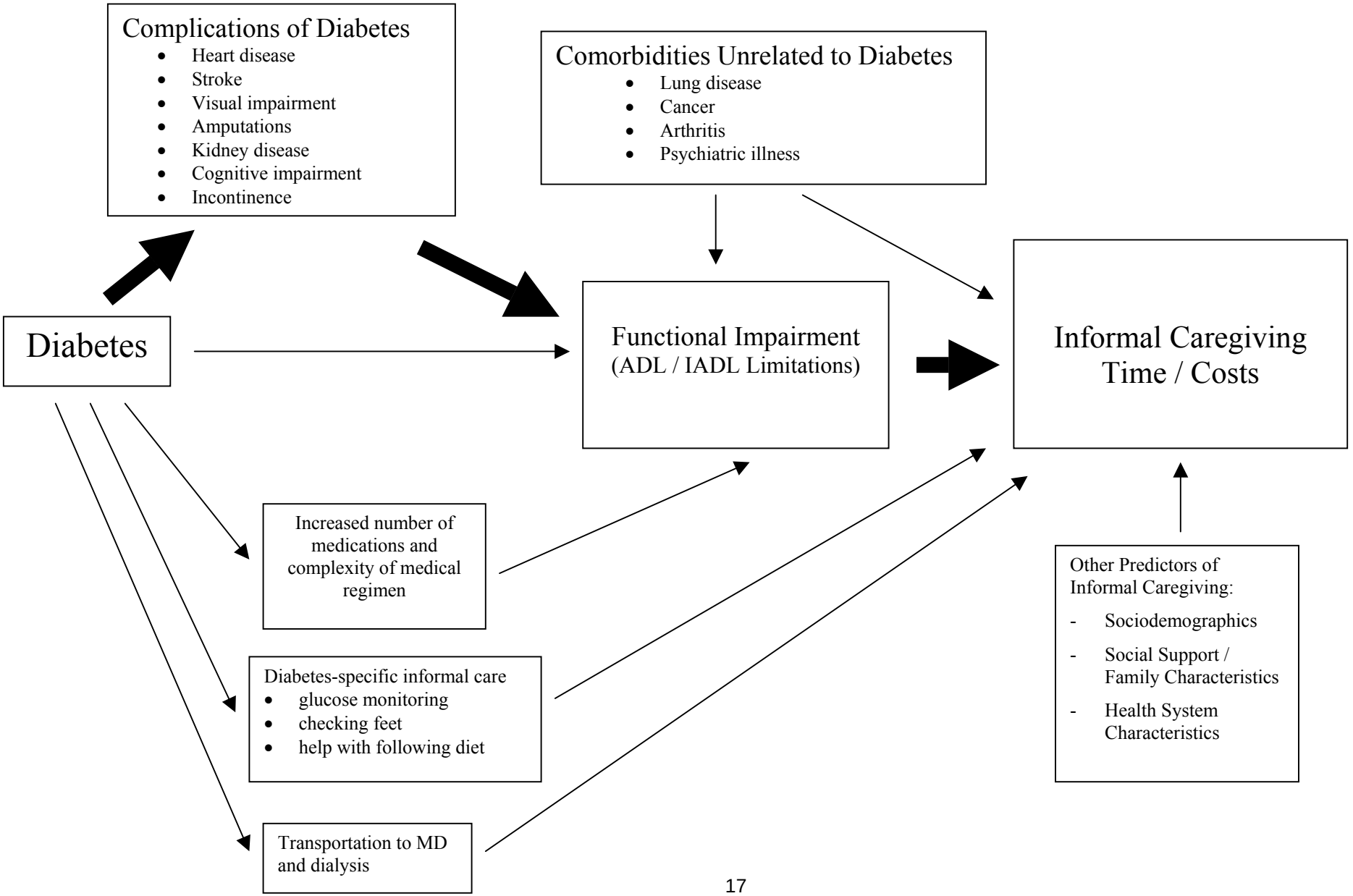

Figure 2. Classification of Diabetes mellitus (DM) status.

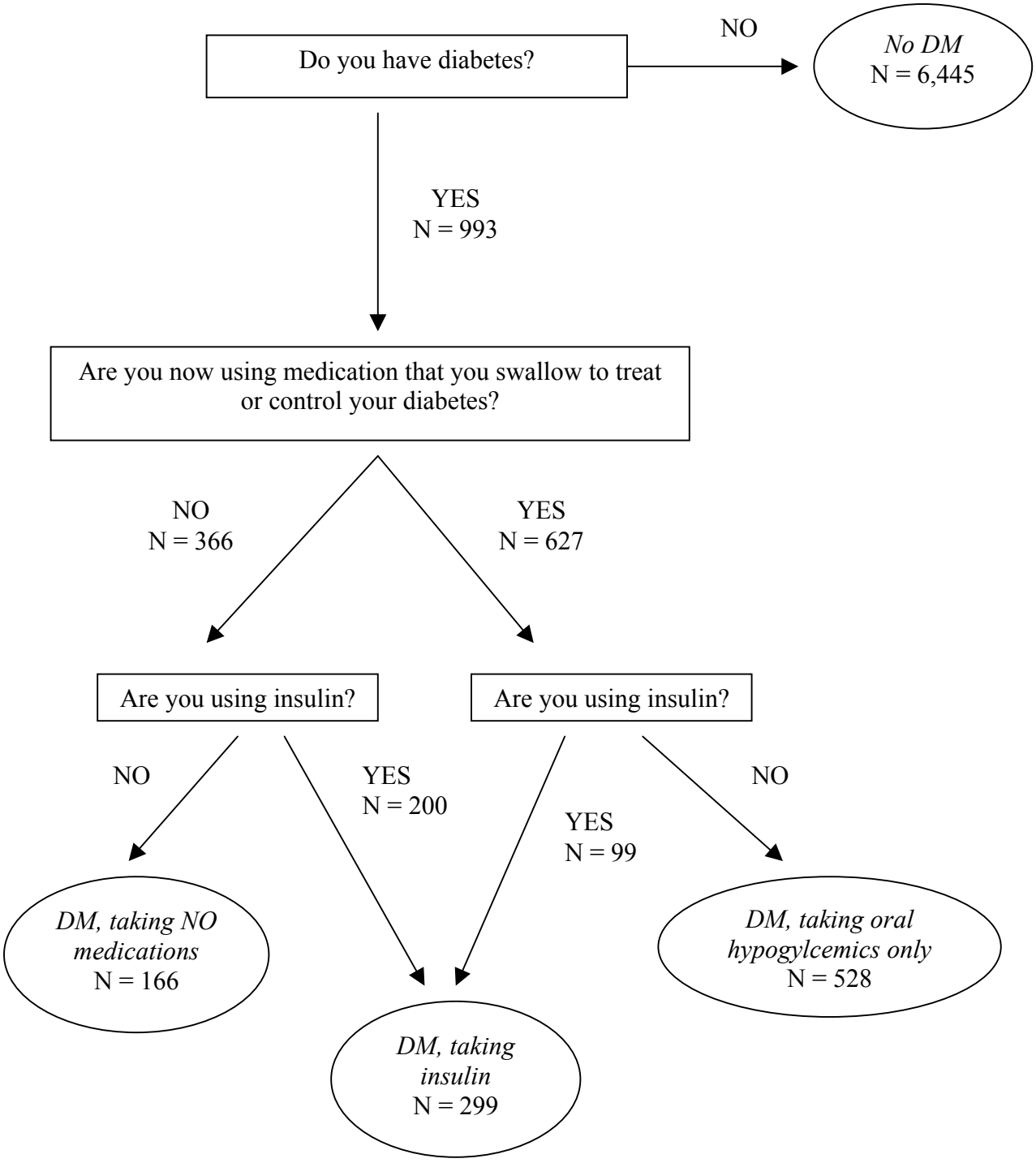

Table 1. Characteristics of the Study Population, by Diabetes Mellitus (DM) Category, (N=7,438)

Variable	Weighted Percentage [a]				P Value
	No DM (N=6445)	DM, taking no medication (N=166)	DM, taking oral medication only (N=528)	DM, taking insulin (N=299)	
Age $(\bar{x} \pm sd)$	77.6 ± 0.1	76.7 ± 0.4	76.9 ± 0.2	76.1 ± 0.3	<.001
70 - 79	66	75	70	78	
80 - 89	29	23	28	20	<.001
≥ 90	4	2	2	2	
Race					
White	89	84	80	76	
African-American	9	14	18	21	<.001
Other	2	2	3	3	
Sex					
Male	37	42	41	40	.2
Female	63	58	59	60	
Living Situation					
Married	50	50	48	50	
Unmarried living with others	14	17	19	19	.03
Unmarried living alone	36	33	33	31	
Net Worth (US $)					
< 38,000	29	38	40	39	
38,000 - 139,000	34	29	31	34	<.001
> 139,000	37	33	30	27	
Education (years)					
< 12	41	46	52	53	
12	31	32	30	27	<.001
≥ 13	28	21	18	20	

Table 1. Characteristics of the Study Population, by Diabetes Mellitus (DM) Category (N=7,438) (cont'd)

Variable	Weighted Percentage [a]				P Value
	No DM (N=6445)	DM, taking no medication (N=166)	DM, taking oral medication only (N=528)	DM, taking insulin (N=299)	
Chronic Conditions					
Heart disease	30	41	40	49	<.001
Stroke	10	16	14	18	<.001
Visual Impairment	8	9	12	21	<.001
Dementia	10	10	9	16	.004
Incontinence	19	22	23	25	.02
Lung disease	12	15	12	13	.5
Cancer	14	15	15	13	.8
Psychiatric problem	11	16	11	11	.3
Arthritis	25	31	30	30	.005
# of Medications $(\bar{x} \pm sd)$	2.25 ± 0.03	2.93 ± 0.16	3.98 ± 0.10	4.62 ± 0.18	<.001
0	22	13	1	2	
1 - 2	40	39	32	21	<.001
≥ 3	38	48	67	77	

[a] Weighted percentage derived using the AHEAD respondent population weights to adjust for the complex sampling design of the AHEAD survey.

Table 2. Activity of Daily Living (ADL) and Instrument Activity of Daily Living (IADL) Limitations, by Diabetes Mellitus (DM) Category, (N=7,438)

Variable	Weighted Percentage [a]				P Value
	No DM (N=6445)	DM, taking no medication (N=166)	DM, taking oral medication only (N=528)	DM, taking insulin (N=299)	
# of ADLs Impaired $(\bar{x} \pm sd)$	0.62 ± 0.02	1.13 ± 0.14	1.03 ± 0.08	1.35 ± 0.13	<.001
0	72	59	60	46	
1 - 3	22	28	29	41	<.001
4 - 6	6	13	11	13	
# of IADLs Impaired $(\bar{x} \pm sd)$	0.53 ± 0.02	0.80 ± 0.10	0.79 ± 0.06	1.09 ± 0.08	<.001
0	72	60	62	46	
1 - 3	24	32	33	45	<.001
4 – 5	4	8	6	9	
ADL Limitation					
Walking across a room	22	33	32	46	<.001
Dressing	12	23	20	30	<.001
Bathing	11	21	20	23	<.001
Transferring	8	15	15	18	<.001
Toleting	4	9	9	10	<.001
Eating	5	13	8	9	<.001
IADL Limitation					
Grocery shopping	17	24	27	36	<.001
Managing money	17	22	23	32	<.001
Cooking	9	14	13	16	<.001
Taking medicines	4	7	8	12	<.001
Using the telephone	5	7	6	9	.02

[a] Weighted percentage derived using the AHEAD respondent population weights to adjust for the complex sampling design of the AHEAD survey.

Figure 3. Regression models for determining factors that affect average weekly informal caregiving hours for diabetes

Model 1	Model 2	Model 3
Diabetes Category	Diabetes Category **Sociodemographics** **Lung Disease** **Cancer** **Psychiatric Problem** **Arthritis**	Diabetes Category Sociodemographics Lung Disease Cancer Psychiatric Problem Arthritis **Heart Disease** **Stroke**

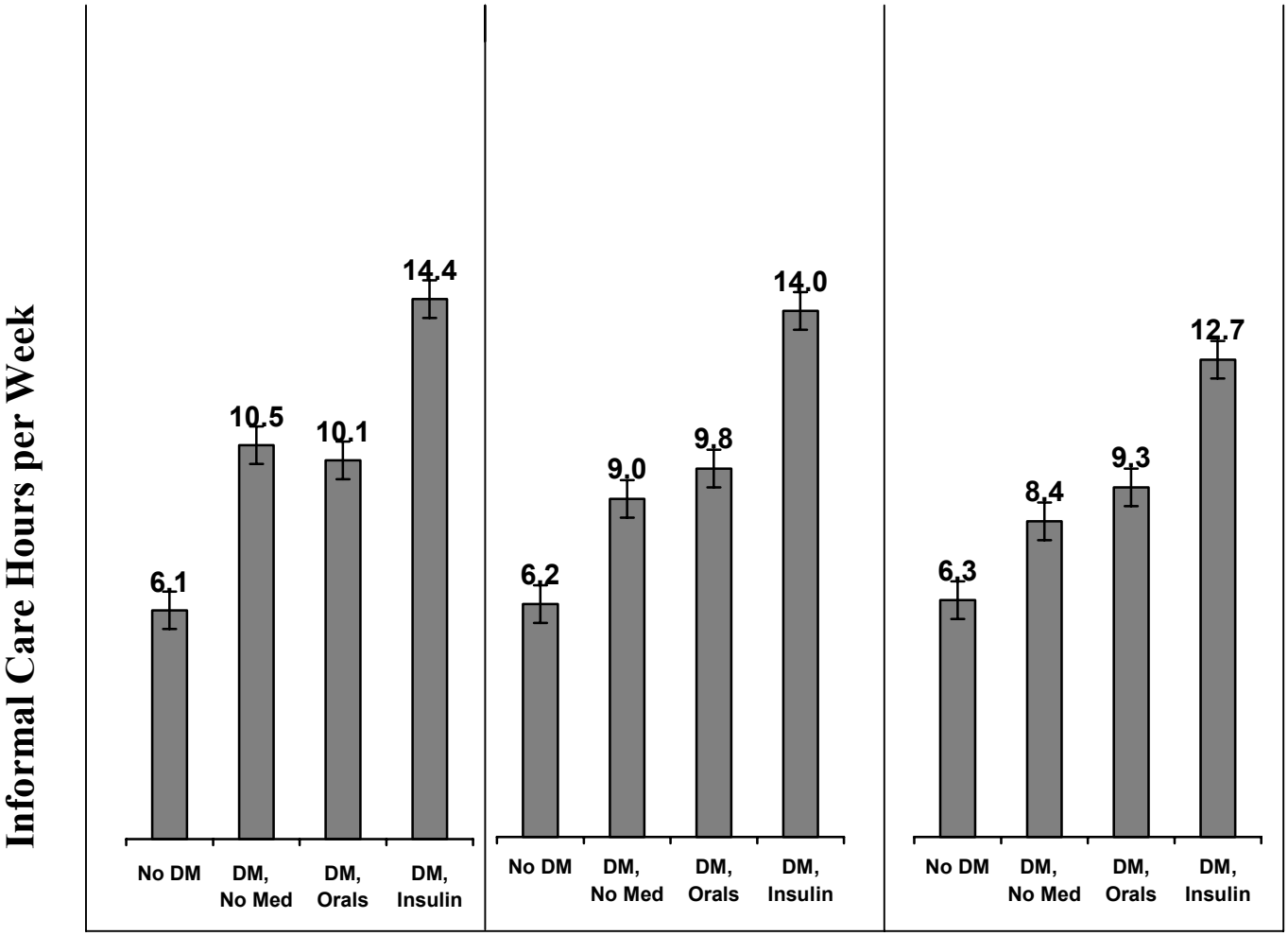

Figure 3. Regression models for determining factors that affect average weekly informal caregiving hours for diabetes (cont'd)

Model 4	Model 5	Model 6
Diabetes Category	Diabetes Category	Diabetes Category
Sociodemographics	Sociodemographics	Sociodemographics
Lung Disease Cancer Psychiatric Problem Arthritis	Lung Disease Cancer Psychiatric Problem Arthritis	Lung Disease Cancer Psychiatric Problem Arthritis
Heart Disease Stroke	Heart Disease Stroke	Heart Disease Stroke
Visual Impairment	Visual Impairment	Visual Impairment
	Dementia **Incontinence**	Dementia Incontinence
		# of Medications

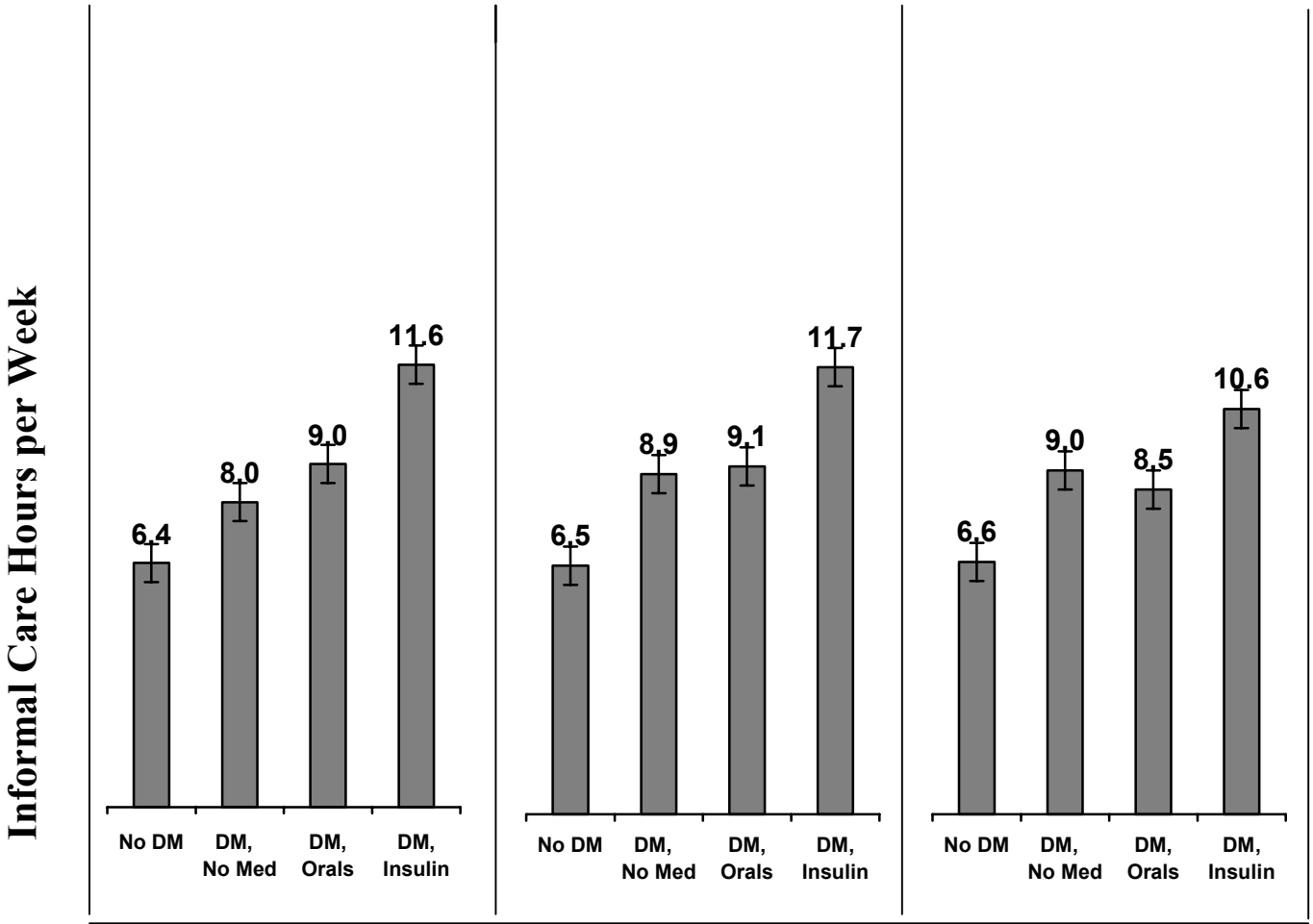

Table 3. Weekly Hours and Yearly Cost of Informal Care, by Diabetes Mellitus (DM) Category

DM Category	Hours per Week (95% C.I.)		Cost per Year (US $) [b] (95% C.I.)	
	Unadjusted	Adjusted [a]	Unadjusted	Adjusted
No DM	6.1 (5.7 – 6.5)	6.6 (6.2 – 6.9)	$2,600 (2,400 – 2,800)	$2,800 (2,600 – 2,900)
DM, taking no medication	10.5 (10.0 – 11.0)	9.0 (8.5 – 9.5)	$4,500 (4,200 – 4,700)	$3,800 (3,600 – 4,000)
DM, taking oral medication only	10.1 (9.6 – 10.6)	8.5 (8.1 – 9.0)	$4,300 (4,100 – 4,500)	$3,600 (3,400 – 3,800)
DM, taking insulin	14.4 (13.8 – 15.0)	10.6 (10.1 – 11.2)	$6,100 (5,900 – 6,400)	$4,500 (4,300 – 4,800)

[a] Adjusted weekly hours of informal care derived from Model 6, which included age, race, sex, living situation, net worth, education, lung disease, cancer, psychiatric problem, arthritis, heart disease, stroke, visual impairment, dementia, incontinence, and number of medications as independent variables.

[b] Yearly cost of informal care was calculated by multiplying the weekly hours of care by $8.17 per hour (national average wage rate for a home health aide in 1998), and then multiplying by 52 (weeks per year).

C.I. indicates confidence interval.

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