

# Informal Caregiving Time and Costs for Urinary Incontinence in Older Individuals in the United States

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**OBJECTIVES:** To obtain nationally representative estimates of the additional time, and related cost, of informal caregiving associated with urinary incontinence in older individuals.

**DESIGN:** Multivariate regression models using data from the 1993 Asset and Health Dynamics Study, a nationally representative survey of people aged 70 and older (N = 7,443).

**SETTING:** Community-dwelling older people.

**PARTICIPANTS:** National population-based sample of community-dwelling older people.

**MEASUREMENTS:** Weekly hours of informal caregiving, and imputed cost of caregiver time, for community-dwelling older people who reported (1) no unintended urine loss, (2) incontinence that did not require the use of absorbent pads, and (3) incontinence that required the use of absorbent pads.

**RESULTS:** Thirteen percent of men and 24% of women reported incontinence. After adjusting for sociodemographics, living situation, and comorbidities, continent men received 7.4 hours per week of care, incontinent men who did not use pads received 11.3 hours, and incontinent men who used pads received 16.6 hours ( $P < .001$ ). Women in these groups received 5.9, 7.6, and 10.7 hours ( $P < .001$ ), respectively. The *additional* yearly cost of informal care associated with incontinence was \$1,700 and \$4,000 for incontinent men who did not and did use pads, respectively, whereas, for women in these groups, the *ad-*

*ditional* yearly cost was \$700 and \$2,000. Overall, this represents a national annual cost of more than \$6 billion for incontinence-related informal care.

**CONCLUSIONS:** The quantity of informal caregiving for older people with incontinence and its associated economic cost are substantial. Future analyses of the costs of incontinence, and the cost-effectiveness of interventions to prevent or treat incontinence, should consider the significant informal caregiving costs associated with this condition. *J Am Geriatr Soc* 50:733–737, 2002.

**Key words:** urinary incontinence; older; disability; informal caregiving; cost of illness

Unintended urine loss is a common symptom among older adults. Between 20% and 30% of older community residents<sup>1–3</sup> and at least 40% of nursing home residents<sup>4,5</sup> are incontinent of urine. Overall, this condition may affect up to 10 million people in the United States. Urinary incontinence is associated with physical and behavioral factors that can impair the quality of a person's life.<sup>6</sup> Specifically, this common disorder can lead to psychological distress,<sup>7</sup> disrupted social relationships,<sup>8</sup> skin breakdown, urinary tract infection,<sup>9</sup> frequent hospitalizations,<sup>10</sup> and nursing home admission.<sup>10</sup> Furthermore, individuals are often embarrassed and frustrated by their incontinence.

The economic costs of urinary incontinence are substantial. The direct medical costs for urinary incontinence have recently been estimated at over \$25 billion, or approximately \$3,500 per incontinent person per year.<sup>11</sup> In the nursing home, urinary incontinence accounts for 3% to 8% of total costs,<sup>12</sup> with the average nursing time spent managing a patient's urinary incontinence being nearly 1 hour per day.<sup>13</sup>

The time and associated cost of informal (unpaid) caregiving for urinary incontinence have not been well described or consistently accounted for in prior studies.<sup>11,14</sup> Because several interventions aimed at better managing patients with urinary incontinence are time or resource in-

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tensive (e.g., programmed toileting), a full elicitation of the costs averted by these interventions is essential to appropriately estimate their cost-effectiveness. If significant informal caregiving costs for urinary incontinence are excluded from consideration, incontinence interventions may be viewed as less cost-effective and therefore may not be adopted in clinical practice.

To this end, we sought to estimate the number of hours, and related cost, of informal care received by continent and incontinent community-dwelling individuals aged 70 and older. Our main goal was to determine the *additional* number of caregiving hours attributable to urinary incontinence, after adjusting for comorbid conditions and socio-demographic characteristics that might independently affect the provision of informal care to older individuals.

## METHODS

### Data

We used the baseline (1993/4) Asset and Health Dynamics among the Oldest Old (AHEAD) cohort of the Health and Retirement Study (HRS) for this analysis. The HRS is a nationally representative longitudinal survey conducted by the Institute for Social Research at the University of Michigan with funding from the National Institute on Aging. AHEAD respondents included 7,443 men and women aged 70 and older at the time of the interview (i.e., born in 1923 or before). Interviews were conducted in person or over the telephone in English or Spanish. Proxy respondents were interviewed in cases where the selected respondents were unable to answer the survey questions independently. A response rate of 80.4% was achieved.<sup>15</sup>

### Definitions

Urinary incontinence was determined by an affirmative response to the question, "During the last 12 months, have you lost any amount of urine beyond your control?" This question was preceded by an introduction designed to acknowledge the potential for embarrassment and to stress the importance of the response, "The next question might not be easy to talk about, but it is very important for research on health and aging." (We have shown that introductions of this sort are a useful method for attending to the possibility of underreporting of incontinence.<sup>16</sup>)

The severity of urinary incontinence was assessed with two questions asked of respondents who answered "yes" to the above question: (1) "On about how many days in the last month have you lost any urine?" and (2) "Do you ever use any absorbent products such as pads, special garments, sanitary napkins, or toilet paper for your urine loss condition?" As in prior studies,<sup>17,18</sup> we found that responses to these two questions were highly correlated: compared with those reporting fewer than 7 days of urine loss, the odds ratio of pad use was 2.0 for those reporting 7 to 20 days of urine loss ( $P < .001$ ) and 5.8 ( $P < .001$ ) for those reporting more than 20 days. For the present analysis, we used the absorbent products (hereafter referred to as "pads") variable as the sole indicator of the severity of incontinence, for sake of simplicity and because the days variable had significant missing data. A separate analysis using the number of days of urine loss showed similar trends in informal caregiving hours to those reported here.

Fifteen respondents (0.2%) had missing data needed to classify their incontinence status and were therefore excluded from the analysis.

### Caregiving Hours

Respondents were identified as recipients of informal care if: (1) a relative or unpaid nonrelative (with no organizational affiliation) provided in-home assistance with any activity of daily living (ADL) (eating, transferring, toileting, dressing, bathing, walking across a room) "most of the time" or (2) a relative or unpaid nonrelative (with no organizational affiliation) provided in-home assistance with any instrumental ADL (preparing meals, grocery shopping, making phone calls, taking medications, managing money) because of a health problem.<sup>19</sup>

The number of hours per week of informal care was calculated using the average number of days per week (in the prior month) and the average number of hours per day that the respondent reported receiving assistance from informal caregivers. The methodology used for calculating weekly hours of care from the AHEAD data has been described previously.<sup>20,21</sup>

### Potential Confounding Variables

Because the goal of the analysis was to quantify the *additional* hours of informal caregiving attributable to urinary incontinence, we controlled for the presence of other comorbid chronic health conditions that might result in the receipt of informal care and for sociodemographic characteristics (age, race, gender, net worth) and living situation (married, unmarried living alone, unmarried living with others). The chronic health conditions (self-reported) controlled for in the analysis included: heart disease, stroke, diabetes mellitus, hypertension, lung disease, cancer, psychiatric problem, and arthritis. We also adjusted for cognitive impairment consistent with dementia as measured by a previously validated cognitive status instrument.<sup>22,23</sup>

### Calculating the Cost of Informal Care

The "opportunity cost" associated with informal caregiving for ADLs is often estimated using the average wage for a home health aide,<sup>24,25</sup> under the assumption that this wage represents the cost of purchasing similar caregiving activities in the market. We used this method to estimate the yearly cost of informal caregiving for each incontinence category by multiplying the 1998 average national wage for a home health aide ( \$8.17 per hour<sup>26</sup>) by the adjusted weekly hours of care and then multiplying by 52 (weeks per year). We then used the national prevalence estimates of incontinence derived from the AHEAD study to determine an estimate of the yearly national cost of informal caregiving associated with incontinence. We performed a sensitivity analysis for annual national caregiving costs using the 10th percentile home health aide wage rate (\$5.90 per hour) as a more conservative estimate of the opportunity cost of caregiver time, and the 90th percentile wage rate (\$10.80 per hour) as a more generous estimate to provide a reasonable range of informal caregiving cost.<sup>26</sup>

### Data Analysis

Because a substantial proportion of respondents received no informal care, and because the distribution of hours

among recipients was highly skewed, we constructed a two-part multivariate regression model.<sup>27,28</sup> For the first part, logistic regression was used to determine the relationship of incontinence to the likelihood of receiving any informal care, adjusting for the above potentially confounding factors. For the second part, we used linear regression to examine the association between incontinence and the natural log of informal care hours among those who received care, again adjusting for the same potentially confounding factors. The results from the two parts of the model were then combined to obtain an estimate of the unconditional effect (not conditioned on receipt of care) of incontinence on weekly hours of informal caregiving. For ease of reporting and interpretation, the results from the regression analyses were retransformed to hours.<sup>29</sup>

Analyses were weighted and adjusted for the complex sampling design of the AHEAD study. We tested for significant interaction effects among the independent variables and performed regression diagnostics to check for influential observations and heteroscedasticity in the residuals. All analyses were performed using STATA Statistical Software, release 6.0 (STATA Corp., College Station, TX). An institutional review board at the University of Michigan approved the HRS/AHEAD study. The data used for this analysis contained no unique identifiers, so respondent anonymity was maintained.

## RESULTS

Descriptive information about the study population is shown in Table 1. About 20% of older individuals reported incontinence. Those with incontinence were older and more likely to be white, female, and unmarried and have low net worth. Individuals with incontinence also had higher rates of each chronic condition, including heart disease, stroke, diabetes mellitus, hypertension, dementia, lung disease, cancer, psychiatric problems, and arthritis. Incontinence was related to significantly higher rates of informal and formal (paid) caregiving.

Gender-specific results for informal caregiving hours and cost, after adjusting for all other covariates using the two-part regression analysis, are shown in Table 2. Men who were continent received, on average, 7.4 hours per week of informal care, those who were incontinent but did not use pads received 11.3 hours per week (or 3.9 *additional* hours of care), and those with incontinence using pads received 16.6 hours per week (or 9.2 *additional* hours or care) ( $P > .001$ ). Women who were continent received, on average, 5.9 hours per week of informal care, those who were incontinent but did not use pads received 7.6 hours per week (or 1.7 *additional* hours of care), and those with incontinence using pads received 10.7 hours per week (or 4.8 *additional* hours or care) ( $P > .001$ ).

Using the 1998 average home health aide wage (\$8.17 per hour), the 3.9 additional weekly hours of informal care for incontinent men with no pad use suggests an additional yearly incontinence-related cost of about \$1,700 per man ( $\$8.17/\text{hour} \times 3.9 \text{ hours/week} \times 52 \text{ weeks/year}$ ). For incontinent men using pads, the additional yearly cost is about \$4,000. For women, the additional yearly caregiving cost is \$700 for those not using pads and \$2,000 for those using pads.

Given the nationally representative sample of the AHEAD study, an estimate of the total informal caregiver time and cost associated with urinary incontinence among community-dwelling people aged 70 and older in the United States can be calculated. Our results suggest that approximately 750,000 men and 1.2 million women were incontinent but did not use pads and that 250,000 men and 1.9 million women were incontinent and used pads. Multiplying these prevalence estimates by the additional yearly cost per person yields a total additional yearly cost in the United States of \$2.3 billion for men and \$4.6 billion for women, for a combined cost of about \$6.9 billion. Using the 10th percentile home health aide wage (\$5.90 per hour) as an estimate of the cost of caregiver time, the total annual national cost would be about \$5.0 billion, and using the 90th percentile wage (\$10.80 per hour) yields an estimate of about \$9.1 billion per year.

## DISCUSSION

By using a national survey of the time spent providing care to community-dwelling people aged 70 and older with various chronic medical conditions, we were able to estimate the informal caregiving time and cost associated with urinary incontinence. Our analysis reveals a clear and consistent pattern; after adjusting for comorbid illness, socio-demographic characteristics, and living situation, older individuals with urinary incontinence received a significantly greater quantity of informal care than those who were continent. Not surprisingly, severe urinary incontinence (as identified by the use of absorbent pads) was associated with the greatest intensity of informal care—an additional 1.3 hours per day (9.2 additional hours per week divided by 7 days per week) for men and 40 minutes per day (4.8 additional hours per week divided by 7) for women. This level of caregiving is significantly greater than that assumed in prior analyses of the economic costs of incontinence.<sup>11,14</sup>

The amount of time spent on informal assistance is an important objective component of “caregiver burden” because, regardless of the subjective experience, caregiving carries an opportunity cost by causing caregivers to give up time that could be devoted to leisure or to work inside or outside the home. Thus, the substantial caregiver time associated with urinary incontinence may be a factor in eventual nursing home admission among older people with incontinence. In one small study, 44% of caregivers indicated that their relative’s loss of urine control contributed to the decision to institutionalize.<sup>30</sup> Another study found that incontinence was a precipitating factor for 13% of 288 new nursing home admissions.<sup>31</sup> The higher prevalence of urinary incontinence in nursing homes than in the community suggests that in-home management of the condition may overwhelm informal caregivers.<sup>32</sup>

Interestingly, we found that men received significantly more hours of informal caregiving than women in each incontinence category. A prior analysis of AHEAD data showed that, on average, men received significantly more hours of informal care, even when level of disability, marital status, and living arrangement were controlled.<sup>33</sup> So some of the gender difference in incontinence-related care found in this study is likely due to sociocultural factors re-

**Table 1. Characteristics of the Study Population, by Incontinence Category (N = 7,428)**

Characteristics	Continent (n = 5,988)	Incontinent, no Pad Use (n = 707)	Incontinent, with Pad Use (n = 733)	P-value
	weighted percentage*			
Age, mean $\pm$ standard deviation	77.2 $\pm$ 0.2	78.1 $\pm$ 0.5	79.3 $\pm$ 0.6	<.001
70–79	69	64	55	
80–89	27	32	37	<.001
$\geq$ 90	3	4	8	
Race				
White	88	87	92	
African American	10	11	7	.04
Other	2	2	1	
Gender				
Male	41	38	12	<.001
Female	59	62	88	
Net worth				
<\$38,000	30	32	36	
\$38,000–\$139,000	34	31	33	.007
>\$139,000	36	37	30	
Living situation				
Married	52	48	36	
Unmarried living with others	14	15	21	<.001
Unmarried living alone	35	37	43	
Chronic conditions				
Heart disease	30	34	40	<.001
Stroke	9	14	19	<.001
Diabetes mellitus	12	15	15	.03
Hypertension	48	54	59	<.001
Dementia	9	10	16	<.001
Lung disease	11	12	17	<.001
Cancer	13	16	21	<.001
Psychiatric problem	10	17	16	<.001
Arthritis	24	30	35	<.001
Caregiving received				
Informal	23	32	43	<.001
Formal	4	7	14	<.001

\*Derived using the Asset and Health Dynamics among the Oldest Old (AHEAD) respondent population weights to adjust for the complex sampling design of the AHEAD survey.

garding the dominant role of women as “caregivers,”<sup>33</sup> but it is also possible that urge and stress incontinence, which vary in prevalence by sex,<sup>34</sup> lead to different amounts of informal care. In addition, the devices and strategies used to manage incontinence in men and women may differ, thereby leading to differences in the informal caregiving required. The AHEAD data did not allow us to determine the type of incontinence or the specific incontinence management strategy (other than the use of pads), so we were unable to directly assess these factors as explanations for differences in incontinence-related caregiving. Further study is needed to better determine the causes and consequences of this gender difference.

We employed methods that likely led to conservative estimates of informal caregiving time and cost. Most importantly, the AHEAD data only include caregiving provided for help with ADLs and instrumental ADLs. The time required for caregivers to perform such incontinence-related tasks as laundering soiled clothes and sheets, cleaning

floors or furniture, or providing transportation to physician visits is not included in the analysis. However, even using these conservative measures, and using the low-range opportunity cost estimate, the national annual cost of incontinence caregiving still reaches about \$5 billion per year.

As with all observational studies, the possibility exists that a variable omitted from our analysis (e.g., another comorbidity) that is correlated with the presence of incontinence and informal caregiving is the “true cause” of the increased caregiving that we found for incontinent older people. Similarly, given the cross-sectional nature of the data, it is difficult to determine definitively whether incontinence is simply *associated* with increased disability (and subsequent informal care to address that disability) or is the actual *cause* of increased disability (e.g., due to an increased risk of falls and fractures<sup>35</sup>). However, we included important sociodemographic measures and other common comorbidities among older people that have previously been shown to influence the level of informal care.

**Table 2. Weekly Hours and Yearly Cost of Informal Care, by Gender and Incontinence Category**

Incontinence Category	Men		Women	
	Weekly Hours* (95% CI)	Yearly Cost (\$)† (95% CI)	Weekly Hours* (95% CI)	Yearly Cost (\$)† (95% CI)
Continent	7.4 (7.0–7.7)	3,100 (2,900–3,300)	5.9 (5.6–6.3)	2,500 (2,300–2,700)
Incontinent, no pad use	11.3 (10.8–11.7)	4,800 (4,500–5,000)	7.6 (7.2–8.0)	3,200 (3,000–3,400)
Incontinent, with pad use	16.6 (16.0–17.2)	7,100 (6,800–7,300)	10.7 (10.1–11.2)	4,500 (4,300–4,800)

\*Adjusted weekly hours of informal care derived from a two-part regression model that included age, race, gender, net worth, living situation, heart disease, stroke, diabetes mellitus, hypertension, dementia, lung disease, cancer, psychiatric problem, and arthritis as independent variables.

†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).

CI = confidence interval.

In addition, as discussed above, our estimate of the time and cost associated with informal caregiving for incontinence is a conservative one, so it is unlikely that we have significantly overestimated the cost of incontinence caregiving because of an omitted variable. Further study should focus on better defining the “causal pathways” by which incontinence may lead to increased caregiving.

Given the high prevalence and cost associated with urinary incontinence, appropriate management is of particular importance.<sup>5,34</sup> The usual management of mild urinary incontinence is based on behavioral modification (e.g., prompted voiding protocols), pelvic exercises (e.g., Kegel maneuvers), and cause-specific pharmaceutical intervention (e.g., oxybutynin, estrogen).<sup>34</sup> For those with moderate to severe incontinence who do not benefit from the above measures, various urinary collection devices are often required.<sup>5,36</sup> These include condom catheters, diapers or undergarments, and indwelling catheters. To accurately determine whether these interventions are cost-effective, all the costs associated with urinary incontinence—direct and informal caregiving—should be included in the analysis. By providing an estimate of the informal caregiving costs associated with urinary incontinence in a nationally representative sample of older Americans, we hope this analysis will inform future investigations of the full societal costs associated with this common condition and the cost-effectiveness of interventions to prevent or treat it.

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