Urinary Incontinence in a National Cohort of Older Women: Implications for Caregiving and Care Dependence

Emmy Yang, BS,¹ Nadra E. Lisha, PhD,² Louise Walter, MD,^{2,3}
Juno Obedin-Maliver, MD/MAS,^{4,5} and Alison J. Huang, MD/MAS²

Abstract

Background: Urinary incontinence (UI) can interfere with older women's ability to perform activities of daily living (ADLs), but little is known about factors that predispose incontinent women to become functionally dependent or compromise their ability to serve as caregivers to others.

Study Design: UI, caregiving, and care-receiving behaviors were assessed by questionnaire in a national sample of community-dwelling older women. Multivariable models evaluated associations between incontinence and care dependence, assessed factors associated with care dependence among incontinent women, and compared health among female caregivers with and without incontinence.

Results: Of the 1703 women, 27% reported weekly or more incontinence and 13% monthly incontinence. Women with weekly or more incontinence were more likely than women without incontinence to report receiving care for ADLs (AOR=2.39, CI=1.61–3.56) or instrumental ADLs (AOR=1.94, CI=1.42–2.63). Compared to 46% of women without incontinence, 60% of women with monthly or weekly incontinence reported unmet care needs ($p=0.0002$). Factors associated with care dependence included more frequent incontinence, older age, marital status, and fair/poor health ($p<0.05$ for all). Overall, 15% of women served as a caregiver for another adult, which did not differ by incontinence status ($p=0.84$), but female caregivers with incontinence reported worse health than those without incontinence ($p=0.0004$).

Conclusions: In this national cohort, older women with incontinence were more likely to be functionally dependent and have unmet care needs than those without incontinence, after adjustment for other factors. At least one in ten incontinent women served as caregivers, despite having worse health than female caregivers without incontinence.

Keywords: urinary incontinence, activities of daily living, caregiving, functional dependence

Background

URINARY INCONTINENCE (UI), or the involuntary leakage of urine, is one of the most common chronic conditions in older women, affecting over half of women aged 60 years or older in the United States.¹ Among community-dwelling older women, UI can interfere with women's ability to carry out their usual activities of daily living (ADLs), making it a potentially important contributor to aging-related disability.² Prior studies have suggested that older women with UI may be more likely to become dependent on the informal care of relatives and friends to continue living in the community.^{3,4}

Nevertheless, limited research has explored the impact of UI on the need for care after controlling for other demographic and health-related factors that can also lead to functional dependence as women age.

At the same time, a substantial proportion of older women with UI report coping with their urine leakage for many years while trying to live independently.⁵ Some of these women may be in the position of providing assistance or serving as informal caregivers to relatives or friends who have even more debilitating functional impairments. In 2015, a report by the American Association of Retired Persons found that women constitute three out of five caregivers in the United

¹Icahn School of Medicine at Mount Sinai, New York, New York.

²Department of Medicine, University of California San Francisco, San Francisco, California.

³Division of Geriatrics, Veterans Affairs Medical Center, San Francisco, California.

⁴Department of Obstetrics, Gynecology, & Reproductive Sciences, University of California San Francisco, San Francisco, California.

⁵Division of Gynecology, Veterans Affairs Medical Center, San Francisco, California.

States and provide more overall caregiving hours than men.⁶ Nevertheless, there has been almost no research on the experience of women who serve as caregivers despite suffering from a chronic condition such as UI.

With the aging of the U.S. population, there has been growing interest in identifying factors that influence the caregiving burden of older adults.^{7,8} In 2008, the Centers for Disease Control established a framework to translate research into practices to alleviate this burden, including identification of factors that lead to care dependence, as well as strategies to preserve the health status of caregivers.⁹ However, despite nearly a decade of attention to this issue, little is known about how UI, one of the most common chronic conditions in older women, affects both the care-receiving needs and caregiving experiences of the older woman population, even though older women constitute the majority of both care receivers and informal caregivers in the United States.⁶

To advance understanding of these issues, we examined the strength and direction of relationships between UI and both care receiving and caregiving in a national cohort of older community-dwelling women. Our goals were to provide new insight into the impact of UI on the need for and provision of care for day-to-day activities, to help guide future strategies for reducing the caregiving burden associated with UI.

Materials and Methods

Setting and participants

We conducted a cross-sectional analysis of data from the National Social Life, Health and Aging Project (NSHAP), an observational population-based study of older community-dwelling U.S. adults. The first NSHAP wave consisted of adults aged 57–85 years recruited from a 2004 area-based national probability sample of older household residents, with oversampling of African Americans and Hispanics.¹⁰ Following the first wave of assessments in 2005–2006, a second wave was conducted from 2010 to 2011, which included respondents followed from the first wave, adults who were contacted but declined or failed to complete a first wave visit, and cohabiting spouses and romantic partners of first wave respondents.¹¹

All NSHAP data were collected through home-based study assessments performed by trained interviewers from the National Opinion Research Center (NORC) affiliated with the University of Chicago, supplemented by computer-assisted questionnaires and leave-behind paper-and-pencil questionnaires. Informed consent for NSHAP was obtained before data collection, and all procedures were approved by the Institutional Review Boards at the University of Chicago and NORC. For this study, we analyzed data from the second NSHAP wave, which included expanded assessments of care receiving and caregiving behavior. This analysis using deidentified data was considered exempt from institutional board review by the University of California San Francisco.

Measurements

UI was assessed by questionnaire measures that have been administered in prior epidemiologic investigations to assess health-related outcomes related to UI, but have not undergone detailed psychometric validation or direct comparison

to pad tests or voiding diaries.^{12,13} Participants were asked, “In the past 12 months, have you had difficulty controlling your bladder, including leaking small amounts of urine, leaking when you cough or sneeze, or not being able to make it to the bathroom on time?” Those responding yes were asked, “How frequently does this occur?” with the response options “a few times a year,” “a few times a month,” “a few times a week,” and “every day.”

To assess functional impairment, participants were asked to report difficulty with completing the following ADLs: (a) walking one block, (b) walking across a room, (c) dressing, (d) bathing or showering, (e) eating, such as cutting up food, (f) getting in or out of bed, and (g) using the toilet, including getting up and down. They also reported difficulty with the following instrumental activities of daily living (IADLs): (a) preparing meals, (b) taking medications, (c) managing money, (d) shopping for groceries, (e) performing light housework, (f) using a telephone, and (g) driving a car.¹⁴ Response options included “no difficulty,” “some difficulty,” “much difficulty,” and “unable to do.” To assess whether participants received care or assistance for these activities, those who reported at least “some” difficulty with an ADL or IADL were subsequently asked whether they received help with that activity.

To assess caregiver status, participants were asked, “Are you currently assisting an adult who needs help with day-to-day activities because of age or disability?” Participants who reported being a caregiver were also asked how many hours a day they provided care with response options, including “less than 2 hours,” “2 hours or more but less than 4,” “4–8 hours,” “more than 8 hours,” and “all of the time.”

Demographic characteristics such as race/ethnicity, education level, and marital status were assessed by questionnaire. Participants were also asked to rate their overall health as poor, fair, good, very good, or excellent, using a standard validated question.¹⁵ Selected comorbid health conditions and history of hysterectomy were also identified from questionnaires.^{16–20} Parity was assessed by asking participants how many children they have given birth to in their life.

Statistical analyses

Statistical analyses were confined to women who contributed data on UI during the second wave of NSHAP. To assess possible bias associated with missing data, chi-square and *t*-tests compared the distribution of age, race/ethnicity, marital status, education level, and overall self-reported health of women who did versus did not contribute UI data.

Demographic and clinical characteristics of women in the analytic sample were examined using weighted descriptive statistics.¹¹ For women who provided information about their UI status, chi-square tests compared the prevalence of care receiving for ADLs and IADLs among women in each of the three following collapsed UI categories: (a) UI a few times a year or less, (b) UI a few times a month, and (c) UI a few times a week or more. Analyses focused on differences in care receiving for “at least one ADL,” “at least one IADL,” as well as for each type of ADL or IADL.

We subsequently developed multivariable logistic regression models to examine independent associations between UI frequency and: (a) care receiving for at least one ADL and (b) care receiving for at least one IADL. Women with UI “at least a few times a week or more” and “a few times a month”

were each compared to women with UI “a few times a year or less.” All models were tested both unadjusted and adjusted for age, race/ethnicity, marital status, education level, and overall self-reported health, as factors that were considered a priori to have high potential to influence care receiving.¹³

The prevalence of participants with an unmet need for care or assistance with any ADL or IADL, defined as reporting difficulty with one or more activities but not receiving help for with at least one of these,²¹ was examined using descriptive statistics. Chi-square tests were performed to assess the difference in the proportion of women with an unmet need for care among those with UI at least a few times a month versus those who had UI a few times a year or less.

Among the subset of women reporting UI at least a few times a month, additional multivariable logistic regression models were developed to examine potential risk factors for: (a) care receiving for at least one ADL and (b) care receiving for at least one IADL. Age, race/ethnicity, marital status, education level, frequency of UI, and overall self-reported health were included in these models as potential risk factors for care dependence among women with UI.

Chi-square tests were used to examine differences in the prevalence of caregiving by UI status, focusing on overall caregiving, as well as caregiving for less than 4 hours per day, 4–8 hours per day, or 8 or more hours per day. Once again, women with UI “at least a few times a week or more” and “a few times a month” were each compared to women with UI “a few times a year or less.”

Among the subset of women who served as caregivers, multivariate linear regression was also used to examine differences in overall self-reported health (modeled as a continuous score ranging from 1 “poor” to 5 “excellent”) among women with UI “at least a few times a month or more” versus “a few times a year or less.”²²

All analyses were conducted using SAS (SAS Institute, Inc., Cary, NC) using survey procedures (*e.g.*, *surveymeans*, *surveyfreq*, and *surveylogistic*). Sampling weights were used to ensure correct calculation of the point estimates. As recommended by NSHAP, we used weight accounting for nonresponse by age and race.¹¹ Stratification and clustering statements were used to calculate standard errors along with the corresponding tests of statistical significance.

Results

Sample characteristics

Of the 3377 wave 2 NSHAP participants, 1839 were women. Of these, 136 (7%) were excluded due to missing information on UI. Compared to women missing UI data, the 1703 women with intact UI data were younger (mean age of 70.9 ± 0.3 versus 72.6 ± 0.8 years, $p = 0.03$), but more likely to have only fair or poor self-reported health (27.9% vs. 7.0%, $p = 0.01$). No significant differences in race/ethnicity, marital status, or education level were detected ($p > 0.05$).

Approximately 75% of women in the analytic sample were aged 65 years or older (Table 1), and 19% were racial/ethnic minorities. Fifty-four percent had experienced at least one episode of UI in the past 12 months, with 13% having experienced UI a few times a year, 13% a few times a month, and 27% a few times a week or more. Overall, 35% of women had difficulty with at least one ADL, and 54% had difficulty with at least one IADL (Table 1).

TABLE 1. SELF-REPORTED DEMOGRAPHIC AND CLINICAL CHARACTERISTICS OF FEMALE RESPONDENTS (N=1703)

	N ^a	%
Demographic characteristics		
Age in years		
Mean age ^b	70.9	± 0.3
65 years or older	1345	75.6
Race/ethnicity		
White	692	79.2
African American	180	10.9
Hispanic	113	7.2
Other	25	2.7
Education level		
Less than high school	194	16.1
High school or equivalent	266	27.3
Some college	342	34.6
Bachelor's or more	214	22.1
Married or living with a partner	1051	58.6
Clinical characteristic		
Self-reported health		
Poor	78	4.3
Fair	343	18.2
Good	583	34.3
Very good	496	29.9
Excellent	199	13.2
Comorbid conditions		
Diabetes	381	20.1
Congestive heart failure	63	15.7
Hypertension	1057	57.8
Cancer other than skin	184	10.8
Arthritis	684	38.9
Number of live births		
0	111	8.0
1	164	11.6
2	390	29.4
3+	755	51.1
Past hysterectomy	210	20.3
Urinary incontinence in past 12 months		
None	819	46.4
A few times a year	197	13.0
A few times a month	222	13.3
A few times a week	227	13.5
Every day	238	13.8
Functional difficulty		
Difficulty with at least one ADL	616	34.9
Difficulty with at least one IADL	972	54.1

Frequencies given as unweighted; percentages are column percentages and given as weighted.

^aMissing data: $n = 8$ for race/ethnicity; $n = 4$ for self-reported health; $n = 2$ for diabetes; $n = 1322$ for congestive heart failure; $n = 4$ for hypertension, $n = 1$ for other types of cancer; $n = 23$ for arthritis; $n = 283$ for parity; $n = 488$ for past history of hysterectomy.

^bAge reported as mean under column header “N” and standard deviation under column header “%”.

ADL, activity of daily living; IADL, instrumental activity of daily living.

Overall care receiving and caregiving

Twelve percent ($N = 226$) of women received care for at least one ADL, and 32% ($N = 592$) received care for at least one IADL. In addition, 13% ($N = 231$) of women served as a caregiver to another adult, and of these caregivers, 26%

FIG. 1. Proportion of Women (a) Receiving Care or (b) Serving as Caregivers, by UI Status. $p < 0.0001$ for test of heterogeneity in care receiving for any ADL by UI frequency. $p < 0.0001$ for test of heterogeneity in care receiving for any IADL by UI frequency. $p = 0.84$ for test of heterogeneity in proportion of women serving as caregivers by UI frequency. $p = 0.31$ for test of heterogeneity in hours per day of caregiving by UI frequency. ADL, activity of daily living; IADL, instrumental activity of daily living; UI, urinary incontinence.

($N = 62$) provided care to another adult for 8 hours or more per day.

Prevalence of care receiving by UI status

The proportion of participants who received care for at least one ADL or at least one IADL increased with increasing frequency of UI (Fig. 1a). The prevalence of care receiving for each specific type of ADL or IADL also tended to increase with increasing frequency of UI, with the exception of taking medications and using a telephone (Table 2).

Adjusted associations between UI and care receiving

After adjusting for age, race/ethnicity, education, marital status, and self-reported overall health, women reporting UI a few times a week or more had an estimated 2.4-fold increased odds of receiving care for any ADL and an estimated 1.9-fold increased odds of receiving care for any IADL, compared to women with UI only a few times a year or less (Table 3). In contrast, no significant differences in care receiving for ADLs or IADLs were detected between women with UI a few times a month versus those with UI a few times or less in adjusted models (Table 3).

Unmet need for care assistance

Of women reporting UI a few times a month or more, 431 (60%) had difficulty carrying out at least one ADL or IADL but did not receive care or assistance for that ADL or IADL. In contrast, 490 (46%) of women with UI only a few times a year or less had difficulty with an ADL/IADL without receiving care for that ADL/IADL ($p = 0.0002$ for difference

between women with UI a few times a month or more versus a few times a year or less).

Risk factors for care receiving among women with UI

Among women who experienced UI at least a few times a month, older age, being married, lower self-reported health, and more frequent UI symptoms were associated with care receiving for at least one ADL in adjusted models (Table 4). Older age, lower self-reported health, and more frequent UI symptoms were also associated with care receiving for at least one IADL.

Prevalence of caregiving by UI status

The prevalence of caregiving did not differ significantly among women with UI a few times a week or more, a few times a month, or a few times a year ($p = 0.84$) (Fig. 1b). Furthermore, the number of hours spent caregiving per day did not differ among the three UI frequency groups ($p = 0.31$).

Self-reported health among caregivers by UI status

Among women who served as caregivers, those who experienced UI a few times a month or more had worse self-reported health scores compared to caregivers with UI a few times a year or less (mean score 2.97 ± 2.77 vs. 3.36 ± 1.01 , $p = 0.0043$).

Discussion

These findings from a national cohort of older women offer new insight into the impact of UI on caregiver burden in the

TABLE 2. PROPORTION OF OLDER WOMEN RECEIVING CARE FOR ACTIVITIES OF DAILY LIVING, BY URINARY INCONTINENCE FREQUENCY

	Urinary incontinence frequency			
	A few times a year or less (N=1016)	A few times a month (N=222)	A few times a week or more (N=465)	p-value
Receipt of care for activities of daily living (ADLs)–N (%)				
Walking one block	56 (4.1%)	14 (5.7%)	62 (13.9%)	<0.0001
Dressing	38 (3.4%)	12 (4.8%)	50 (10.7%)	<0.0001
Walking across a room	25 (2.1%)	8 (3.0%)	44 (10.0%)	<0.0001
Bathing or showering	34 (3.0%)	13 (5.1%)	41 (7.8%)	0.0010
Getting in and out of bed	21 (2.3%)	5 (2.0%)	34 (6.5%)	0.002
Eating	13 (1.1%)	4 (2.0%)	25 (5.2%)	0.0002
Using toilet	18 (1.7%)	5 (3.0%)	25 (4.7%)	0.02
Receipt of care for instrumental activities of daily living (IADLs)–N (%)				
Driving a car	95 (8.4%)	24 (10.5%)	91 (9.8%)	<0.0001
Performing light housework	109 (9.6%)	36 (13.7%)	119 (25.4%)	<0.0001
Shopping for groceries	83 (7.1%)	28 (11.4%)	93 (19.6%)	<0.0001
Preparing meals	65 (5.4%)	26 (11.2%)	84 (17.4%)	<0.0001
Managing money	37 (3.1%)	11 (4.8%)	47 (9.5%)	<0.0001
Taking medications	20 (1.7%)	5 (2.0%)	21 (3.6%)	0.07
Using telephone	11 (1.2%)	4 (1.0%)	15 (2.8%)	0.09

Percentages are column percentages and given as weighted.

p-value for chi-squared test of heterogeneity for rates of care receiving between three UI frequency groups.

United States. Urinary incontinence was associated with increased care dependence for nearly all ADLs, independent of overall health status and multiple demographic factors. Among women experiencing UI at least a few times a week, over 20% received care for at least one ADL, and over 40% received care for at least one IADL, more than twice the rate of care receiving among women with UI only a few times a year or not at all. These findings suggest that UI may be an important contributor to functional dependence in older women and that the prevention and treatment of UI may be important to preserving women's ability to live unassisted in the general population.

Our results also reveal an unmet need for care among older community-dwelling women with UI. Up to 60% of incontinent women who had difficulty with an ADL or IADL were not receiving assistance for at least one of these activities. This gap was substantially greater among women with UI versus women without UI, pointing to a potentially important public health need for additional resources to support older women with UI in the community. Prior research has shown that nearly half of women with UI do not seek or receive treatment for their UI.²³

Our findings suggest that many women with UI may also fail to obtain assistance with day-to-day activities.

At the same time, a smaller but nontrivial proportion (15%) of women in this cohort still provided care or assistance to other functionally impaired adults. Interestingly, this proportion did not differ significantly between women with frequent versus minimal UI, even though female caregivers with frequent UI tended to report worse overall physical health relative to caregivers with minimal UI. These findings should be interpreted in the context of prior research suggesting that many caregivers are in a vulnerable position of putting aside their own health needs to address the more acute needs of a loved one.²⁴ According to the National Alliance for Caregiving and American Association of Retired Persons, almost half of caregivers to older adults felt that they did not have a choice in assuming their role as a caregiver.⁶ Our study may highlight the need for clinicians to ask about and provide appropriate treatment for urinary symptoms in older female caregivers, with the goal of preserving their own independence, as well as supporting them in caring for others.

TABLE 3. UNADJUSTED AND ADJUSTED ODDS OF CARE RECEIVING OR CAREGIVING AMONG OLDER WOMEN, BY URINARY INCONTINENCE FREQUENCY

<i>Frequency of urinary incontinence</i>	<i>Receipt of care for any ADL</i>		<i>Receipt of care for any IADL</i>		<i>Caregiving for another adult</i>	
	<i>Unadjusted OR (95% CI)</i>	<i>Adjusted OR (95% CI)^a</i>	<i>Unadjusted OR (95% CI)</i>	<i>Adjusted OR (95% CI)^a</i>	<i>Unadjusted OR (95% CI)</i>	<i>Adjusted OR (95% CI)^a</i>
A few times a week or more vs. a few times a year or less	3.45 (2.33–5.11)	2.39 (1.61–3.56)	2.58 (1.88–3.52)	1.94 (1.42–2.63)	1.10 (0.63–1.92)	1.15 (0.69–1.94)
A few times a month vs. a few times a year or less	1.86 (1.09–3.19)	1.69 (0.98–2.92)	1.31 (0.87–1.97)	1.24 (0.78–1.97)	1.19 (0.63–2.25)	1.17 (0.62–2.22)

^aAdjusted models control for age, race/ethnicity, education level, marital status, and self-reported health.

AOR, adjusted odds ratio; CI, confidence interval.

TABLE 4. DEMOGRAPHIC AND CLINICAL CHARACTERISTICS ASSOCIATED WITH CARE RECEIVING AMONG WOMEN WITH URINARY INCONTINENCE

<i>Participant characteristics</i>	<i>Receipt of care for any ADL adjusted OR (95% CI)</i>	<i>Receipt of care for any IADL adjusted OR (95% CI)</i>
Age (per 5-year increase)	1.29 (1.09–1.52)	1.33 (1.16–1.51)
Race/Ethnicity		
Black vs. White	1.41 (0.71–2.78)	0.96 (0.50–1.86)
Hispanic, non-Black vs. White	1.56 (0.69–3.48)	0.75 (0.41–1.40)
Other vs. White	4.32 (0.95–19.6)	2.74 (0.35–22.28)
Marital Status		
Married or living with a partner vs. no spouse or partner	2.04 (1.16–3.58)	1.40 (0.89–2.19)
Educational background		
High school or less vs. at least some college or vocational school	1.53 (0.88–2.67)	1.22 (0.86–1.74)
Self-reported health		
Fair or poor vs. excellent, very good, or good	9.34 (5.79–15.04)	5.49 (3.46–8.71)
Urinary incontinence frequency		
A few times a week or more vs. a few times a month ^a	1.56 (1.05–2.32)	1.66 (1.04–2.64)

Odds ratios and confidence intervals were derived from multivariable logistic regression models, in which all variables displayed in the table were included simultaneously.

Women were included in this analysis if they reported urinary incontinence at least a few times a month
OR, odds ratio.

Our research provides population-based evidence to corroborate prior studies among nursing home residents and hospitalized older adults that reported associations between UI and impaired functional status.^{25,26} Our results also extend the findings of a prior study conducted in the first wave of NSHAP, which reported increased care dependence for several types for ADLs in women with daily UI, although data on care dependence for IADLs and on caregiving behavior were not available at that time.^{13,14} Among women with UI at least a few times a month, we further identified multiple risk factors for functional dependence, including older age, poor or fair self-reported health, and more severe or frequent UI symptoms. Knowledge of these risk factors may aid clinicians in identifying incontinent patients who are at greatest risk of losing their ability to live independently.

Our analysis benefits from a national sample of older adults and characterization of UI symptoms, caregiving, and care receiving, as well as assessment of a variety of factors with the potential to influence caregiving or care-receiving behaviors. However, our study has several important limitations. First, the cross-sectional design of our research did not allow for longitudinal assessment of changes over time. Second, while efforts were made to protect participants' privacy when sensitive questions were asked, underreporting of UI symptoms and other sensitive information is possible in this study.^{23,27} Furthermore, UI symptoms were assessed through questionnaire measures that have not been validated against voiding diaries or other measures such as pad tests. Care receiving and caregiving were also assessed by participant report, and participants may not have been completely accurate in their recall or reporting of caregiving hours.

Conclusions

Our research provides important new findings that demonstrate the extensive care support needs of older women

living with UI, as well as the prevalence and health-related impact of UI among older female caregivers living in the community. Not only are incontinent women in the community more likely to be functionally dependent but also they are more likely to have an unmet need for assistance with ADL, compared to women with minimal UI. Despite having UI, at least one in ten older incontinent women may provide assistance to other adults, while coping with overall worse health than caregivers without UI. In light of current imperatives to reduce the burden of caregiving in the United States, our findings provide evidence to support the need for new public health initiatives focused on UI to help many older women remain independent and provide care for loved ones in the community.

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Address correspondence to:

Alison J. Huang, MD/MAS

Department of Medicine

University of California San Francisco

1545 Divisadero Street, Box 0320

San Francisco, CA 94115-1732

E-mail: alison.huang@ucsf.edu