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Prevalence of and Risk Factors for Urinary Incontinence in Home Hospice Patients

Bilal Chughtai [a,*], *Dominique Thomas* [a], *David Russell* [b], *Kathryn Bowles* [b], *Holly Prigerson* [c,d]

[a] *Department of Urology, Weill Cornell Medical College, New York-Presbyterian Hospital, New York, NY, USA;* [b] *Visiting Nurse Service of New York, New York, NY, USA;* [c] *Division of Geriatrics and Palliative Medicine, Department of Medicine, Weill Cornell Medicine-New York Presbyterian, New York, NY, USA;* [d] *Center for Research on End of Life Care, Weill Cornell Medicine-New York Presbyterian Hospital, New York, NY, USA*

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Abstract

Urinary incontinence (UI) is a debilitating and embarrassing condition that is prevalent among aging males and females. Little is known about UI in the home hospice setting. We sought to determine UI prevalence and risk factors in a cohort of 15 432 home hospice patients over 4 yr. Most of the study patients were female (59%) and aged ≥75 yr. This was a retrospective observational study and no patients were excluded. The median length of service was 19 d. Approximately one-third of patients were diagnosed with UI during their hospice stay. Female sex and age were associated with a greater risk of UI. Diagnoses that increased the risk of UI included dementia and stroke. The risk of UI diagnosis was lower among those without a health care proxy, as well among those with higher Palliative Performance Scale scores. UI affects a substantial number of patients in home hospice and there are no guidelines for its diagnosis or mitigation. There is a pressing need to further understand the impact of UI on home hospice patients.

Patient summary: We investigated the prevalence of urinary incontinence (UI) among home hospice patients. Approximately one-third of patients were diagnosed with UI during their hospice care. Female sex, age, dementia, and stroke were associated with a greater risk of UI. Guidelines are required for UI diagnosis and mitigation in home hospice care.

* Corresponding author. Department of Urology, Weill Cornell Medicine, 425 East 61st Street, New York, NY 10065, USA. Tel. +1 646 9624811; Fax: +1 646 9620140.
E-mail address: bic9008@med.cornell.edu (B. Chughtai).

Urinary incontinence (UI) is described as the involuntary loss of urine [1]. UI is a common debilitating and embarrassing condition that afflicts both aging males and females [2] and is associated with poor quality of life. Little is known about UI prevalence and risk factors in home hospice. Home hospice patients are burdened by numerous comorbidities and much of the burden of care is upon the patient or caregiver, thus making them a particularly

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susceptible to UI. We sought to determine the prevalence and risk factors associated with UI in a large, diverse, urban home hospice setting.

We conducted a cohort study of patients served by an urban nonprofit hospice agency between January 2013 and May 2017. Patient data were obtained from prospectively collected electronic medical records. The institutional review board at the Visiting Nurse Service of New York approved all study procedures.

UI was defined as any uncontrolled loss of urine and was diagnosed based on patient self-reports and clinical observations during home visits. Sociodemographic characteristics included sex, age, race, marital status, primary caregiver, health care proxy (HCP), and referral source. ICD-9-CM and ICD-10 codes were used to identify the primary diagnosis and to calculate the Charlson comorbidity index [3,4]. The Palliative Performance Scale (PPS) score was documented at the time of admission as a measure of functional status, for which a score of 10 denotes totally bed-bound needing total assistance, while 60 indicates reduced ambulation, with occasional assistance needed [5].

Mean and percentage values were used to describe the characteristics of the study population. Multivariable Cox proportional-hazards regression was used to model the association between various sociodemographic and clinical characteristics and UI-free survival. Follow-up began on the first day of hospice service. Patients were censored at the time of death or discharge from hospice. Statistical significance was set at $p < 0.05$ for all analyses.

A total of 15 432 patients were included in the study, and slightly less than one-third of patients had UI at any time during their hospice stay ($n = 4906$, 32%). Most patients were female (59%), aged ≥75 yr, and of white non-Hispanic ethnicity (50%). While most patients were not currently married (57%), the majority had a primary caregiver (83%) or an appointed health care proxy (83%). The average PPS was 36.0, indicating a need for substantial or total assistance with self-care tasks (Table 1).

Table 1 – Characteristics of the study population receiving home hospice care between January 2013 and May 2017

Variable	Result
Total population, *n* (%)	15 432 (100)
Female, *n* (%)	9105 (59)
Mean age, yr (standard deviation)	78 (14.8)
Age group, *n* (%)	
18–64 yr	2967 (19)
65–74 yr	2674 (17)
75–84 yr	3632 (24)
≥85 yr	6159 (40)
Race/ethnicity, *n* (%)	
White non-Hispanic	7737 (50)
Hispanic	3261 (21)
African American	2579 (17)
Asian or other	1855 (12)
Not currently married, *n* (%)	8843 (57)
No primary caregiver, *n* (%)	2653 (17)
No health care proxy, *n* (%)	2590 (17)
Primary payer, *n* (%)	
Medicare	8421 (55)
Managed Medicare	3688 (24)
Commercial/private insurance	1926 (13)
Managed Medicaid	819 (5.3)
Medicaid	578 (3.7)
Primary diagnosis, *n* (%)	
Cancer	8148 (53)
Dementia	2233 (15)
Congestive heart failure	1278 (8.3)
Stroke	639 (4.1)
Pulmonary disease	555 (3.6)
All other diagnoses	2772 (18)
Mean Charlson comorbidity index (standard deviation)	3.2 (2.2)
Mean Palliative Performance Scale score (standard deviation)	36 (12.5)

The median length of hospice service was 19 d (mean 60.0, standard deviation [SD] 109.0), with the majority having died or been discharged within 30 d of admission (60%). Nursing represented the most frequent type of professional service provided to patients (mean 2.4 visits/wk, SD 2.2). Patients also received care from home health aides (mean 5.7 h/wk, SD 9.8).

The median follow-up was 17 d for patients who were not diagnosed with UI during their hospice stay. The UI-free survival probability was 0.99 (95% confidence interval [CI] 0.99–0.99) for day 15 and 0.93 (95% CI 0.92–0.94) for day 30 of hospice enrollment. Multivariable analyses for patients who did not present with UI at hospice admission (Table 2) revealed that female sex (hazard ratio [HR] 1.30, 95% CU 1.16–1.45) and age (HR 1.02, 95% CI 1.01–1.02) were associated with risk of UI diagnosis during the hospice stay. Protective factors for UI included the absence of a health care proxy (HR 0.44, 95% CI 0.35–0.56). A higher risk of UI was observed for hospice patients with a primary diagnoses of dementia (HR 1.68, 95% CI 1.43–1.98) and stroke (HR 1.72, 95% CI 1.35–2.19). Referral to hospice from a non-hospital setting was also associated with a higher risk of UI (HR 1.11, 95% CI 1.01–1.24). Higher PPS scores were protective against UI (HR 0.98, 95% CI 0.97–0.98). Supplementary analyses revealed that patients with UI had greater service utilization involving more frequent visits from social workers (HR 1.04, 95% CI 1.02–1.06), spiritual counselors (HR 1.08, 95% CI 1.05–1.10), and physicians (HR 1.03, 95% CI 1.00–1.07).

We found that three of every ten home hospice patients were diagnosed with UI. This finding is consistent with our previous results for intensive care units, where more than one-third of patients suffered from UI during the last week of life [6]. Women were at higher risk of UI, in agreement with previous studies on community-dwelling adults, with women experiencing twice the UI rate compared to men. We found that a higher PPS score, indicating better performance status (less assistance needed), was associated with a lower risk of UI. Patients without a health care proxy also had a lower risk of UI which may indicate a delay in diagnosis for those who are incapable of making health care decisions on their own behalf.

Referral to home hospice from settings other than a hospital, i.e. skilled nursing, was also associated with a higher risk of UI. Referral from a non-hospital setting represents an indicator of greater frailty, which was reflected in lower PPS scores. Dunphy and Amesbury [7] compared referral patterns between hospice and home care patients, and found that home care patients had more

Table 2 – Multivariable Cox proportional-hazards model of time to urinary incontinence among patients without urinary incontinence on hospice admission (n = 12 138) [a]

Variable	HR (95% CI)	p value
Female	1.30 (1.16–1.45)	<0.001
Age	1.02 (1.01–1.02)	<0.001
Race/ethnicity		
White non-Hispanic	Reference	
Hispanic	1.09 (0.95–1.24)	0.259
African American	1.16 (1.00–1.34)	0.055
Asian or other	1.19 (1.01–1.41)	0.047
Marital status		
Currently married	Reference	
Not currently married	0.93 (0.83–1.04)	0.203
No primary caregiver	0.88 (0.76–1.03)	0.112
No health care proxy	0.44 (0.35–0.56)	<0.001
Primary payer		
Medicare	Reference	
Managed Medicare	1.06 (0.94–1.19)	0.347
Private insurance	0.65 (0.48–0.87)	0.005
Managed Medicaid	0.95 (0.66–1.37)	0.789
Medicaid	0.95 (0.71–1.27)	0.704
Primary diagnosis		
Cancer	Reference	
Dementia	1.68 (1.43–1.98)	<0.001
Congestive heart failure	1.08 (0.90–1.30)	0.306
Stroke	1.72 (1.35–2.19)	<0.001
Pulmonary disease	0.92 (0.72–1.17)	0.558
All other diagnoses	1.42 (1.20–1.67)	<0.001
Charlson comorbidity index	1.02 (0.99–1.05)	0.122
Palliative Performance Scale score	0.98 (0.97–0.98)	<0.001
Referral source		
Hospital	Reference	
Other setting	1.11 (1.01–1.24)	0.041
R^2	0.04	

HR = hazard ratio; CI = confidence interval.
[a] Patients were censored at the time of death or discharge. Patients who presented with incontinence on admission to hospice care were excluded from the Cox model. The Cox model was adjusted for gender, age, race/ethnicity, marital status, absence of a primary caregiver, absence of a health care proxy, primary insurance payer, primary diagnosis, Charlson comorbidity index, Palliative Performance Scale score, and hospice referral source.

challenges on assessments of pain, dyspnea, and anxiety/depression, which probably translates to higher rates of UI. Perhaps referral from home care represents an indicator of greater frailty and functional dependency.

A cancer diagnosis was protective for UI, whereas a diagnosis of dementia or stroke was associated with a significantly greater risk of UI. This may be multifactorial, including effects on cortical inhibitory function, mobility, and administration of diuretic medication, which may contribute to UI [8].

Limitations to our study include a lack of information on UI type (stress, urge, mixed, overflow) or severity and management, but given the vulnerability of this population, patients would probably not have tolerated this type of assessment. UI diagnosis was determined on the basis of any single patient self-report and/or observation by hospice providers; thus, some cases of UI may have been missed owing to a lack of understanding, fear, or embarrassment. Furthermore, we were unable to discern with certainty whether participants identified as having UI during their hospice care did not have the condition on admission. Other risk factors for UI included parity, body mass index, and benign prostatic hyperplasia. Although we agree that these are very important assessment points, these factors are very difficult to evaluate in the end-of-life setting and data were not routinely collected by the nursing staff as part of their standard clinical assessment. Notwithstanding the limitations, this is the first study on UI prevalence and risk factors in home hospice. Given that many of the risk factors identified are not modifiable, this is the first study to identify how common UI is in this population and to characterize patients likely to be diagnosed with UI during their hospice care. Further research is needed to explore how health care providers are assessing and treating UI in the home hospice setting.

UI has been associated with anxiety and depression, and early detection of UI is important given it has been equated to a state worse than death and profoundly affects a patient's dignity [2,9,10].

Author contributions: Bilal Chughtai had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: Chughtai, Prigerson.
Acquisition of data: Russell, Bowles.
Analysis and interpretation of data: Russell, Thomas.
Drafting of the manuscript: Thomas, Russell.
Critical revision of the manuscript for important intellectual content: All authors.
Statistical analysis: Russell.
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Supervision: Chughtai, Prigerson, Bowles.
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