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Content of Home-Based Dementia Care: Adverse Consequences of Unmet Toileting Needs

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Abstract

Despite high intensity caregiving support, those with dementia may experience adverse consequences because the care they receive does not match their care needs. This study evaluates the relationship between content of care (i.e., specific assistance with toileting) and adverse consequences (i.e., toileting accidents because no one was there to help) in a population of community-dwelling Medicare beneficiaries with dementia and impairment in toileting enrolled in the National Health and Aging Trends Study (NHATS). Only two-thirds of individuals received specific assistance with toileting, which was associated with a reduced risk of adverse consequences related to toileting in a multivariable model adjusted for key variables including high intensity caregiving (OR 0.36, 95% CI 0.23 - 0.58). In order to ensure care meets the needs of those dementia living in the community, it is important to consider not only the quantity but also the content of care received.

Introduction

Because of both preference and evidence of cost effectiveness, a growing number of older adults with dementia receive long-term care in the community rather than in nursing homes (Kitchener et al., 2005). Yet evidence suggests that those with dementia living in the community experience high levels of adverse consequences of unmet care needs and are particularly reliant on family and paid caregivers (Black et al., 2013; Kasper et al., 2015). Not unexpectedly, those with the most care needs also have the highest number of unmet care needs and related adverse consequences (Beach et al., 2018; Gaugler et al., 2005).

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Conflict of Interest:

We have no conflict of interest to declare.

These adverse consequences persist despite receipt of high intensity caregiving; more hours of care are associated with more rather than less unmet care needs (Beach et al., 2018; Beach & Schulz, 2017). While this may be because the increasing care hours are unable to keep pace with growing care needs, it may also be due to a failure to effectively direct care at existing unmet care needs. For example, a person with dementia living alone at home may have multiple caregivers and receive substantial hours of support (e.g., a daughter who cooks and handles finances and a paid caregiver who bathes her) but may still experience adverse consequences related to a specific care need because no one is available, trained, or willing to help with that task.

Despite evidence-based, caregiver-driven approaches like prompted toileting (Drennan et al., 2012), nearly 50% of older adults with dementia living in the community report adverse consequences related to toileting (e.g., accidentally wetting or soiling oneself), which are associated with institutionalization (Beach et al., 2018; Dramé et al., 2012; Gaugler et al., 2005; Grimsland et al., 2019). Because many factors contribute to what a caregiver does when providing care in the home (e.g. caregiver skills, patient willingness to accept help, timing and frequency of patient needs), we conceptualize the content of care (i.e., the specific tasks a caregiver performs) as being distinct from overall caregiving intensity and more relevant to adverse consequences. We hypothesized that among community-dwelling older adults with dementia and impairment in toileting, specific assistance with toileting (more than commonly assessed markers of high care like high hours of care or high numbers of helpers) would be associated with less adverse consequences related to toileting.

Methods

Study Population

Our data were drawn from the nationally representative National Health and Aging Trends Study (NHATS), a longitudinal study of late-life disability and function among Medicare beneficiaries 65 years old that began in 2011 and was replenished in 2015 (Kasper & Freedman, 2020). NHATS conducts annual in-person interviews and cognitive and physical performance tests with participants or proxies. Among all community-dwelling individuals with probable dementia at the time of interview in 2011 and/or 2015 (n=1,938), we focused on those with impairment in toileting (n= 618).

Measures

Dementia Status—Dementia status was determined using criteria for probable dementia established by NHATS which incorporated self-report of dementia, proxy responses to the Alzheimer's Disease (AD)-8 screening tool, and a cognitive interview that assessed memory, orientation, and function (Kasper et al., 2013).

Functional Impairment—NHATS participants or proxies are asked their ability to perform each of a series of functional tasks (activities of daily living ADLs including eating, getting out of bed, showering, toileting, and dressing; instrumental activities of daily living IADLs including laundry, shopping, meal preparation, medication management, getting around outside, bills and banking, addressing money matters, and going to the doctor) in

the last month. We defined impairment in a given ADL or IADL based on report that a particular activity was done with difficulty, done with help, or not done.

Receipt of Care—If help with any functional task is received, the helper is identified and additional information about each helper is obtained, including relationship to study participant, hours of help provided, and whether care was paid or unpaid. High intensity caregiving was measured via hours of care (≥ 40 hours caregiving per week) and number of helpers (≥ 3 helpers). Those who received help with toileting were defined as receiving specific assistance with toileting.

Adverse Consequences—Participants are asked whether during the past month they experienced an adverse consequence related to toileting (i.e., “did you ever accidentally wet or soil your clothes because no one was there to help you get to or use the toilet or it was too difficult to get to or use the toilet by yourself?”)

Additional measures—We assessed additional sociodemographic, caregiving, functional, and clinical variables (Table 1). Multiple imputation estimation was used to account for missingness in Medicaid and income. Date of death was obtained from NHATS and the linked Medicare Master Beneficiary Summary file.

Analysis

We evaluated the proportion of individuals who received specific assistance with toileting and evaluated the overlap among specific assistance with toileting and two measures of high intensity caregiving (i.e., high hours of care and high number of helpers). We used Chi-square and Student's t-test to examine differences between those who did and did not experience adverse consequences related to toileting. Finally, we tested if the association between specific assistance with toileting and adverse consequences related to toileting persisted when controlling for patient sociodemographic, clinical and caregiver variables.

All analyses were conducted using NHATS sampling weights to account for selection probabilities and were clustered at the individual level to account for multiple observations. All analyses were performed using Stata, version 16 (College Station, TX). The Johns Hopkins University Institutional Review Board approved the NHATS protocol and all participants provided written informed consent. This study was approved by the Mount Sinai Institutional Review Board.

Results

Among community-dwelling adults with dementia and impairment in toileting, more than half (56%) reported an adverse consequence related to toileting in the last month. Only 67.3% received specific assistance related to toileting. 59.5% received 40+ hours of caregiving per week and 48.3% had 3+ helpers. While 25.7% of the sample had all three characteristics, 15.8% of the sample had only specific assistance with toileting only, suggesting receipt of specific assistance with toileting was related to, yet distinct from other markers of high intensity caregiving (Figure 1).

As compared to those with no adverse consequences related to toileting, those who reported accidentally wetting or soiling themselves were less likely to receive specific assistance with toileting (57.6 % vs. 79.3%, $p<0.01$) and more likely to receive Medicaid (i.e., dually-eligible) (38.9% vs. 28.3%, $p=0.03$) (Table 1). There were no differences in report of adverse consequences related to toileting based on whether or not individuals received high intensity caregiving (i.e. 40 hours per week caregiving, 3 helpers).

The association between adverse consequences related to toileting and less specific assistance related to toileting persisted in a multivariable model adjusted for sociodemographic variables (age, female, white, has Medicaid), caregiving variables (married, high hours of care, high number of helpers), and clinical and functional variables (ADL dependence, hospitalization in the last year) (OR 0.36, 95% CI 0.23-0.58) (Table 2). Medicaid status was no longer independently associated with adverse consequences.

Discussion

Specific assistance with toileting was associated with less adverse consequences related to toileting, regardless of other markers of high intensity caregiving (i.e., high hours of care, high number of helpers) among a nationally representative sample of community-dwelling older adults with dementia. This finding has important clinical, research, and policy implications and should compel further examination of the content of care received by those with dementia living in the community.

If and how a caregiver performs a needed care task depends on the nature of the task itself as well as the unique circumstances of individuals and their caregivers. This is certainly true with toileting: the intimacy required with care related to toileting as well as the physical challenges of providing such care may result in both older adults and their caregivers resisting needed toileting care even when caregivers are present (King et al., 2018). These findings likely have implications for most self-care tasks. For example, an individual with severe arthritis may remain in bed even when she wants to get up because her caregiver cannot lift her.

In the clinical encounter, focused elicitation of information about what specific tasks caregivers are actually performing is necessary because numerous caregivers providing many hours of care does not ensure individual care needs are addressed. This is important both for those living in private residences and those in assisted living facilities, where lack of consistent regulation results in highly variable care provision. Providing toileting care in particular is challenging; family caregivers may need additional training and paid caregivers may need additional case-specific supervision. Similarly, assessment of the content of care is important for researchers to consider as they conceptualize and measure dynamic caregiving arrangements (Hepburn & Siegel, 2020). In particular, evaluations of the impact of caregivers on care recipients should explicitly evaluate the content of care so that accurate conclusions about this impact can be drawn.

Attention to content of care also informs the development of policy solutions to the looming shortage of dementia caregivers. While adding more direct care hours for those with

functional impairment in the community may address existing unmet care needs (LaPlante et al., 2004), this is often not a logistically or financially feasible option, especially for care needs like toileting that can happen at any time of the day or night. Instead, models of community-based care that focus on meeting care needs for a larger population (e.g., Program for All-Inclusive Care of the Elderly, MediCaring Accountable Care Communities) may be better able to focus on addressing specific unmet care needs (Branch et al., 1995; Lynn & Montgomery, 2015).

This study has several limitations. The cross-sectional information captured in this study cannot evaluate the dynamic qualities of either unmet care needs or caregiving support, nor can it evaluate causal relationships between content of care and adverse consequences. In addition, proxies reporting on behalf of those with dementia may not accurately report care received. Yet this work illustrates an important concept in caregiving that has not been explored in previous literature and can serve as the foundation for future studies examining change in caregiving tasks over time and outcomes beyond those related to toileting. Finally, we were not able to assess other factors that may impact adverse consequences related to toileting (e.g., behavioral symptoms of dementia, quality of care delivered). However, by focusing on only those with known impairment in toileting, we were able to definitively differentiate needed care from care received.

In order to meet the complex care needs of those with dementia living in the community, we need to know not simply how much care individuals are receiving, but also the content of that care. Content of care assessment should be a part of both clinical care and ongoing caregiving research in order to ensure that those living in the community with dementia have care matched to their needs.

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The Johns Hopkins University Institutional Review Board approved the NHATS protocol and all participants provided written informed consent. This study was approved by the Icahn School of Medicine at Mount Sinai Institutional Review Board.

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Figure 1:
Overlap Between Receipt of Specific Assistance with Toileting and Other Markers of High Intensity Caregiving

Table 1

Characteristics of Community-Dwelling Older Adults with Dementia and Impairment in Toileting (n=579)

	Full Sample (n=618)	No Adverse Consequence (n=252)	Adverse Consequence (n=346)	P-value
Sociodemographic Variables				
Age, Mean (SD)	83.1 (8.0)	83.8 (8.2)	82.6 (7.9)	0.16
Female, %	64.8	63.8	65.5	0.71
White, Non-Hispanic, %	66.6	67.4	66.0	0.74
High school education, %	61.0	63.8	58.9	0.32
Income, Mean (SD)	36,265 (76,040)	39,297 (62,126)	33,878 (85,428)	0.50
Medicaid, %	33.7	27.7	38.3	0.03
Married, %	37.1	40.3	34.6	0.25
Interview Conducted With Proxy, %	71.9	75.8	68.8	0.10
Caregiving Variables				
Number Children, Mean (SD)	3.1 (2.2)	3.0 (2.2)	3.1 (2.1)	0.47
Lives Alone, %	28.7	28.5	28.9	0.93
Primary Caregiver Spouse, %	26.6	27.5	25.8	0.71
Resides in Assisted Living, %	24.8	24.1	25.3	0.80
Lives in Metro Area, %	86.2	84.9	87.3	0.47
Any Paid Help, %	38.4	36.3	40.0	0.45
Total Hours Help/ Week, Mean (SD)	82.9 (81.2)	89.7 (83.2)	77.6 (79.3)	0.11
40 Hours Help/ Week, %	59.5	62.5	57.1	0.27
Number of Helpers, Mean (SD)	2.7 (1.6)	2.7 (1.6)	2.8 (1.6)	0.33
3 Helpers, %	48.3	49.5	47.3	0.66
Specific Assistance with Toileting, %	67.3	79.3	57.8	<0.01
Clinical and Functional Variables				
Medical Conditions, Mean (SD)	5.0 (2.1)	4.8 (2.1)	5.1 (2.1)	0.10
Depression Screen Positive, %	50.2	49.0	51.1	0.68
Hospitalized in the Past Year, %	47.5	49.8	45.7	0.40
ADL ^a Impairment, Mean (SD)	5.2 (1.1)	5.3 (1.1)	5.1 (1.2)	0.14
IADL ^b Impairment, Mean (SD)	3.8 (1.6)	3.8 (1.6)	3.7 (1.6)	0.73
Died in the Next Year, %	26.2	31.0	22.5	0.08

^aSix ADLs evaluated: eating, getting out of bed, showering, toileting, dressing, getting around inside^bFive IADLs evaluated: laundry, shopping, meal preparation, medication management, bills and banking

Table 2

Multivariable Logistic Regression Model Evaluating Association Between Specific Assistance With Toileting and Adverse Consequences Related to Toileting

	Odds Ratio	P-Value	95% CI
Assistance with toileting	0.36	<0.01	0.23 – 0.58
40 hours of help per week	0.96	0.85	0.61 – 1.50
3 helpers	0.90	0.64	0.59 – 1.38
Age	0.98	0.33	0.95 – 1.02
Female	1.12	0.63	0.70 – 1.80
Married	1.12	0.63	0.70 – 1.80
White	0.93	0.76	0.59 – 1.47
Medicaid	1.38	0.20	0.84 – 2.28
Hospitalization in the last year	0.90	0.61	0.59 – 1.36