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New or Worsening Symptoms and Signs in Community-Dwelling Persons with Dementia: Incidence and Relation to Use of Acute Medical Services

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	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N
Employment or		X		X		X		X		X		X		X		X
Affiliation																
Grants/Funds		X		X		X		X		X		X		X		X
Honoraria		X		X		X		X		X		X		X		X
Speaker Forum		X		X		X		X		X		X		X		X
Consultant		X		X		X		X		X		X		X		X
Stocks		X		X		X		X		X		X		X		X
Royalties		X		X		X		X		X		X		X		X
Expert Testimony		X		X		X		X		X		X		X		X
Board Member		X		X		X		X		X		X		X		X
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Abstract

Background/Objectives—To understand the range of symptoms that present to family caregivers of community-dwelling persons with Alzheimer's disease and related dementias (ADRD).

Design—Six-month longitudinal prospective study to identify the incidence of new or worsening symptoms and their association with acute care medical service use.

Setting—Community-based sample of volunteers from multiple states.

Participants—136 patient-caregiver dyads with a range of dementia severity.

Measurements—44 symptoms and signs common in older persons and/or persons with dementia; frequency of emergency department visits, hospitalizations, and death; and associations between reported symptoms and acute medical care.

Results—During a mean of 5.7 months' follow-up, new or worsening organ-specific (90% of participants), nonspecific (89%), and behavioral (88%) symptoms were common, with the average caregiver reporting seven new or worsening symptoms. Most common were worsening confusion (74%), decreased activity (64%), agitation (57%), hallucinations/delusions (45%), voice and speaking problems (45%), not eating or drinking (44%), and stress/anxiety (41%). Hospitalization and emergency department use occurred respectively in 19% and 20% of participants, and were associated with organ-specific symptoms (OR 3.15, $P=0.02$), less so with nonspecific symptoms (OR 2.27, $P=0.07$), and very little with behavioral symptoms (OR 1.44, $p=0.38$). Within each symptom category, certain symptoms were significantly associated with acute medical service use.

Conclusion—Family caregivers of persons with ADRD must respond to a variety of medical, nonspecific, and behavioral symptoms. The high incidence of new or worsening symptoms and of acute medical care use suggests a need to better target symptom evaluation and management in caregiver education.

Keywords

dementia; comorbidity; community dwelling; symptoms

The direct cost of care for persons with Alzheimer's disease and related dementias (ADRD) was \$225 billion in 2015, in part due to their acute medical care needs.¹ Compared to age-matched peers without ADRD, persons with ADRD are three times more likely to be hospitalized and 74% more likely to have that hospitalization identified as potentially avoidable.^{2,3} These hospital admissions are primarily to treat non-ADRD conditions, reflecting the high prevalence of comorbidity in the ADRD population. For example, 29–33% of people with ADRD have coronary artery disease, 28–31% have congestive heart failure, 22–26% have diabetes, and 17–27% have chronic obstructive pulmonary disease.⁴

Not surprisingly, people with ADRD frequently experience organ-specific and nonspecific symptoms. In addition, they exhibit a variety of behavioral symptoms, such as apathy, depression, agitation, aggression, irritability, delusions and anxiety.⁵ Although behavioral

symptoms have been studied in relation to caregiver burden and dementia care, they have not been examined as potential indicators of medical illness; similarly, non-specific and organ-specific symptoms have received little attention. For example, although we know that some symptoms are common in persons with dementia – examples include insomnia, excessive sleepiness, falls, visual impairment, urinary incontinence, and dental caries,^{6–10} little research has quantified the overall extent of new and worsening symptoms among people with ADRD.

Underscoring how little information exists regarding medical comorbidities among people with ADRD, the majority of symptom research and resources for caregivers address behavioral as opposed to medical symptoms.¹¹ For family members assisting a relative with ADRD who lives at home, this omission is a tremendous gap in the literature, making the management of these symptoms challenging. Cognitive impairment diminishes the ability of people with ADRD to express, articulate, and self-manage when symptoms arise.^{3,4} As a result, caregivers frequently have the responsibility to evaluate often unclear symptoms or signs and then decide whether to attempt home management or seek medical attention. At the same time, caregivers are usually ill-prepared to assess new or worsening symptoms arising in people with ADRD since they frequently lack medical training.^{4,12,13} Yet symptoms are of crucial importance in health care, and may often be linked to patient or caregiver anxiety, declining health, and medical care use.¹⁴

To address the dearth of information on symptoms presenting to caregivers of persons with ADRD, we enrolled and studied for six months 136 dyads consisting of persons with ADRD living at home in the community and the family member most involved in care. Our objectives were to determine the most common symptoms of people with ADRD as reported by caregivers; to identify the relative incidence of behavioral, organ-specific, and nonspecific medical symptoms in these individuals; to record the frequency of emergency department visits, hospitalizations and death during six months of follow-up; and to determine which symptoms were associated with an increased risk of hospitalization and emergency department use. We hypothesized that caregivers would need to address many diverse symptoms, that many signs of potential acute care needs would be non-specific and behavioral, and that hypoactive behavioral symptoms would more commonly be associated with acute care use than hyperactive ones.

Methods

To study new or worsening medical events among persons with ADRD living in the community, we enrolled in a six-month longitudinal prospective study caregiver-care recipient dyads who met the following eligibility criteria: The care recipient needed to have a diagnosis of ADRD; reside in the community (not in assisted living or a nursing home); not be in a comatose state; not be receiving Hospice care; and not be expected to transition to a nursing home, assisted living community, or Hospice within six months. Caregivers needed to be 21 years of age or older; the person most involved in care and care decisions for the care recipient; have face-to-face contact with the care recipient at least weekly; and, because this was part of a larger study of decision-making, to use the internet at least three times a week. Potential study participants were recruited by notices placed in newsletters or

websites of *AlzConnected* (a nationwide forum for caregivers), the *Duke Family Support Program*, *Alzheimer's North Carolina*, *Geriatric Care Management*, the *Penn Memory Center*, *Guiding Lights*; and during presentations by the project principal investigators to caregivers.

A total of 272 caregivers responded, of whom 111 were ineligible (most commonly because the care recipient was in assisted living or a nursing home). Of the remaining 161, 143 (89%) were enrolled, with the most common reasons for non-enrollment being due to the burden of completing interviews (nine respondents) and the study having met its recruitment goal of 140 dyads (nine respondents). All participants were explained all elements of consent, provided verbal informed consent, and received by mail a copy of the consent form, according to procedures approved by the Institutional Review Board of the University of North Carolina at Chapel Hill.

Each participating caregiver was interviewed at baseline, three, and six months. Response rates were 95% at three months (N=136) and 85% at six months (N=122), with all but one nonresponse due to inability to reach the caregiver. Participants who died or received institutional placement during the first three months were not followed at six months, since the study was of community-living persons only. Over the six-month study period, 771 person-months of data on symptom and sign incidence (mean follow-up 5.7 months) were recorded from the 136 participants for whom we obtained at least three months of data.

The baseline interview included demographic information about the caregiver (e.g., age, race, relationship to care recipient, education, self-rated health) and care-recipient (e.g., age, education, date of ADRD diagnosis, functional status, cognitive status). Cognitive status was measured using the Cognitive Performance Scale (CPS), a 7-point informant-generated measure that categorizes individuals' cognitive status as mild, moderate, or severe, and which correlates well with the Mini-Mental State Examination.^{15,16} Follow-up interviews asked about the occurrence during the previous three months of new or worsening symptoms and signs; and about the incidence of death, hospitalization, emergency department visits, or nursing home or assisted living placement.

The list of new or worsening symptoms was developed based on the most common reasons for ambulatory visits of persons aged 65 and older to U.S. medical practices;^{17,18} reports of common nonspecific symptoms in the elderly;^{19,20} lists of common behavioral symptoms in ADRD;^{21–23} and symptoms related to the most common reasons for hospitalization of community-dwelling persons with ADRD.²⁴ Modifications to the list were made during a six month feasibility trial involving 18 ADRD caregivers that preceded this study. The final list included the following 44 presenting complaints: abdominal pain, aggression, agitation, blood in the urine, blood pressure, breathing problems, chest pain, chewing and swallowing, constipation, cough, decreased activity, dental problems, depression, diabetes, diarrhea, falls, fever, hallucinations or delusions, head injury, hearing loss, hip fractures, hoarding and hiding, leg swelling, nosebleeds, not eating or drinking, not taking care of self, pain with urination, passing out, pressure ulcers, red or swollen eye, resisting care, sexual behavior, skin injuries, sleep problems (daytime), sleep problems (nighttime), stress and anxiety, suspected abuse and neglect, urinary incontinence, concern about possible urinary tract

infection, vision problems, voice and speaking problems, vomiting, wandering, and worsening confusion. Because the study sought to determine the relationship between types of symptoms/signs and use of acute care services, for analytical purposes the list was classified into organ-specific, nonspecific, and behavioral symptoms/signs. Behavioral symptoms were further sub-classified as hypoactive and hyperactive, as literature suggests hypoactive behaviors are more often signs of incipient illness.²⁵

All interviews were data entered, double entered, and cleaned for accuracy. Descriptive statistics were generated for caregiver and care-recipient characteristics, new or worsening conditions, and hospitalizations and emergency department visits. Generalized linear mixed models were used to test the association of the report of a specific new or worsening symptom in the prior three months with the report of acute medical care (hospital or emergency department) use during the same time period. Because most caregivers reported on two 3-month periods, a random effect for caregiver was included in the model. A logit link yielded estimates of the odds ratio comparing care recipients with a symptom to those without. Analyses were completed using SPSS for Windows, version 23. Analyses were adjusted for multiple comparisons using the false discovery rate adjustment method of Benjamini and Hochberg.²⁶

Results

Characteristics of the 136 caregiver-care recipient dyads are displayed in Table 1. Among the participants with ADRD, the average age was 78 years, 63% were female, and the sample included a range of individuals in terms of length of time since diagnosis (40% diagnosed more than three years ago), degree of cognitive impairment (60%, had moderate impairment), and physical health (roughly one third were in poor, intermediate, and generally good health). Slightly over half required physical assistance with bathing and dressing; 45% had urinary incontinence; 33% needed assistance with transferring; and 17% needed assistance with eating. Of the caregiver respondents, 82% were white, 34% were spouses and 57% were daughters or daughter-in laws, 89% had at least some college education, and 23% had training in a health field.

At least one new or worsening symptom was reported by 99% of caregivers during the study period (Table 2). By category, organ-specific (90%), behavioral (89%) and non-specific (88%) symptoms were equally common. The average caregiver reported 7 new or worsening symptoms during the study period, and 76% of caregivers reported all three categories of symptoms. The ten most common symptoms reported were worsening confusion (74%), decreased activity (65%), agitation (57%), hallucinations/delusions (46%), voice and speaking problems (46%), not eating or drinking (44%), stress/anxiety (42%), aggression (37%), not taking care of self (36%), and falls (36%). Little association was noted between dementia severity and the prevalence of specific symptoms; of all symptoms studied only constipation and pressure ulcers were significantly associated with dementia stage, with both being more common in advanced diseases (Table 2).

During an average of 5.7 months' of follow-up, six persons with ADRD died, 31 hospitalizations occurred; 41 emergency department visits without hospitalization occurred;

and 10 participants were relocated to assisted living communities or nursing homes. Of the 31 hospitalizations, the most common reasons included infection (35%); symptoms related to ADRD progression such as dehydration or behavioral outburst (16%); and cardiovascular events (13%). A wide range of problems resulted in emergency department visits without hospitalization, of which 20% were for gastrointestinal symptoms (abdominal pain, vomiting or diarrhea) and 34% for either falls, passing out, or seizures.

By category, organ-specific symptoms were most strongly associated with acute medical service use (OR 3.17, $P=0.02$); behavioral symptoms were not associated with acute medical service use (OR 1.44, $p=0.38$); and nonspecific symptoms had an intermediate association trend (OR 2.08, $P=0.10$). The strongest associations with acute medical service use were in relation to eight individual symptoms (all $p<0.01$), at least one of which was from each symptom category (Table 3): voice and speaking problems (OR 2.33, $p=0.010$), skin injuries (OR 3.49, $p=0.001$), concern about urinary tract infection (OR 3.47, $p=0.006$), blood pressure concerns (7.07, $p<0.001$), pressure ulcers (OR 4.48, $p=0.007$), hallucinations/delusions (OR 3.72, $p<0.001$), falls (OR 3.20, $p<0.001$), and night-time sleep problems (OR 2.40, $p=0.014$). In addition, eight uncommon organ-specific complaints (chest pain, diabetes, head injury, passing out, vomiting, blood in the urine, nosebleeds, and hip fracture) together were moderately associated (OR 2.01, $p=0.001$) with medical service use.

Discussion

This study of 136 persons with ADRD living at home documented that family caregivers are presented with a wide variety of new or worsening medical, behavioral, and nonspecific symptoms. During an average of 5.7 months of follow-up, virtually every respondent reported one or more new or worsening symptoms; the average number reported was seven, and three-quarters of study participants reported at least one symptom from each of our three symptom categories. Among individual symptoms, those most commonly reported included worsening confusion, decreased activity, agitation, voice and speaking problems, hallucinations/delusions, and stress/anxiety. During the follow-up period, participants reported 31 hospitalizations and 41 emergency department visits without hospitalization. Associations were identified between these acute events and a number of specific symptoms (but not others) from within each category; thus, the individual symptom rather than the category is most important in judging a complaint's severity and likelihood that it represents a problem requiring medical attention.

New or worsening organ-specific symptoms were reported by 90% of participating caregivers. The most common were voice and speaking problems (46% of respondents), urinary incontinence (32%), and skin injuries (28%). Changes in speech occur early in ADRD and continue to progress throughout its course,²⁷ but to our knowledge there are no prior reports of the incidence of caregiver-reported voice and speaking problems in ADRD. Beyond language decline associated with ADRD and Lewy body dementia, speaking problems can represent cerebrovascular events, which could explain the association of these symptoms with acute medical service use (OR 2.33, $p=0.01$). Similarly, to our knowledge this is the first study of the incidence of skin injuries in persons with ADRD living in the community; however, the reported incidence is understandable as skin tears have been

reported in 8–44% of elderly individuals,²⁸ and our study population was at increased risk for skin injury due to both age-associated skin thinning and a high prevalence of falls. The fact that these injuries were associated with acute medical service use (OR = 3.46, $p=.001$) suggests that this might be a target of caregiver education around prevention and home care. The incidence of new or worsening urine incontinence is also understandable, as incontinence is common in ADRD and increases as the disease progresses.²⁹ The frequency of incontinence-related complaints is particularly important in community-dwelling persons with ADRD, as it is a key factor in the decision for assisted living or nursing home placement.²⁹

The two most commonly-reported nonspecific symptoms – decreased activity and new or worsening eating or drinking– reflect the psychomotor slowing that is common as dementia progresses. Such symptoms are common in community-dwelling persons with ADRD, with reported prevalence figures of 66% for "hypophagia,"⁵ and 61–88% for hypoactive behaviors as a group.³⁰ Interestingly, hypoactive symptoms such as these have received much less attention than hyperactive behavioral symptoms such as agitation and aggression, although they have been reported to be harbingers of new or worsening medical problems²⁵. In nursing home residents, for example, hypoactive symptoms such as lethargy (LR 7.3), weakness (LR 7.0), and decreased appetite (LR 6.0) were highly predictive of acute illness.²⁵ In our community sample, however, they were only modestly associated with use of acute care medical services, most likely due to differences between the community and nursing home settings, the severity of the symptoms themselves, or the caregivers' abilities to attend to the symptoms. When associated with illness, these symptoms may well represent hypoactive delirium, a condition that is under-recognized by healthcare professionals.³¹

The association of falls with hospitalizations and emergency department visits is not surprising and is consistent with findings from a 12-month study of 626 community-dwelling persons with ADRD in Spain.⁹ Nighttime sleep problems were another nonspecific symptom significantly associated with acute medical service utilization (OR 2.40, $p=0.01$). Although decreased sleep quality and quantity are part of both aging and ADRD physiology,⁸ this finding suggests that new or worsening nighttime sleep problems should not be dismissed as an age-related or ADRD-related symptom without further consideration.

The most common behavioral symptoms reported were worsening confusion (74% of respondents), agitation (57%), and hallucinations/delusions (46%). These findings are consistent with prior studies of these symptoms.⁵ Worsening confusion poses an especially thorny problem, not only for caregivers but also for medical professionals. Acute delirium is considered a medical emergency, and a defining feature is worsening confusion.³¹ However, in this sample its very high incidence and lack of association with hospitalizations or emergency department visits suggests that worsening confusion is not typically an indicator of acute delirium. On the other hand, hallucinations/delusions was significantly associated with acute medical service utilization (OR 3.72, $p<0.001$) and thus may be a better indicator of delirium than altered mental status. In a study of community-dwelling persons with ADRD, hallucinations and delusions were significantly associated with metabolic disturbances including hyperthyroidism, hypothyroidism, hypernatremia, hyponatremia and hyperkalemia.³² These findings contrast with another study, which found no significant

association between delusions and illness;²⁵ however, that population was nursing home residents, and assessments were done by nursing assistants rather than informal caregivers as the other study. This may explain the discordant findings, because family caregivers report greater frequency and severity of hallucinations and delusions than non-related caregivers.³³ As such, family caregivers may better recognize new or worsening delusions or hallucinations as signs of new or worsening medical conditions than formal caregivers.

The only other behavioral symptom significantly associated with hospitalization and emergency department visits was depression (OR 2.32, $p=0.017$), a finding that supports literature indicating that depression in persons with ADRD is associated with increased comorbidity, decreased functioning, poorer cognition and increased hospitalization.³⁴ As such, new or worsening depression is likely a risk factor of new medical illness, though it could also represent a symptom of new disease.

There are, of course, limitations that must be considered in interpreting these data. While in many demographic aspects (age, race, illness stage) we achieved a relatively representative sample of the ADRD population, our cohort distinctly over-represented caregivers with advanced education, as is common in studies involving volunteers; additionally, our sample included a relatively high frequency (23%) of persons with training in health care. Thus, detection of signs and symptoms may have been better than in most studies, or, alternately, these informed caregivers may not have reported signs and symptoms they considered to be of little concern. In addition, since our study gathered data using caregiver report, we were unable to determine whether and to what extent our patients' dementia diagnoses were accurate. Furthermore, we employed an unvalidated checklist that, though well informed by the literature and a pilot study, could have missed one or more common symptoms, or the wording of our symptoms descriptions may have been interpreted differently by our various study participants. Additionally, the associations we found between symptoms and acute medical care use could have been moderated by other, potentially preventable factors, such as ambulatory care experiences or medication adverse events; however, addressing such questions was beyond the scope of this research. Finally, our sample size at 136 resulted in statistics of only modest precision.

Nevertheless, our results provide new data on the range and type of signs and symptoms encountered by caregivers of persons with ADRD. The fact that over a period of less than six months an average caregiver had to address seven diverse new or worsening symptoms underscores the challenging role that family caregivers play in health care. The high incidence rates of certain complex, often under-appreciated symptoms, such as voice/speaking problems, urinary incontinence, and worsening confusion, indicate areas where improved resources for caregivers might be beneficial. Similarly, the signs and symptoms associated with acute medical care use, such as skin injuries, pressure ulcers, and hallucinations/delusions, suggest the potential benefit of specifically targeting these conditions in educational activities, to help caregivers anticipate and manage medical events that are more likely to occur.

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Table 1

Characteristics of Participating Care Recipients and Family Caregivers (N=136)

Characteristics of the Person with Dementia	N (%) or Mean (range)
Age, mean (SD)	78 (42–99)
Gender, female	85 (63%)
Length of time since diagnosis:	
< 3 years	57 (42%)
3 – 4 years	32 (24%)
5 years	46 (34%)
Cognitive impairment (CPS): ^a	
mild	10 (7%)
moderate	82 (60%)
severe	44 (33%)
Physical health as rated by caregiver:	
very good or excellent	49 (36%)
good	41 (30%)
poor or fair	46 (34%)
Needs hands on assistance/total assistance for:	
Bathing	71 (52%)
Dressing	72 (53%)
Toileting	49 (36%)
Transferring	45 (33%)
Continence	61 (45%)
Eating	23 (17%)
Medication administration	126 (93%)
Characteristics of the Family Caregiver	
Relationship to care recipient	
Spouse	46 (34%)
Daughter	66 (49%)
Daughter-in-law	11 (8%)
Other ^b	13 (9%)
Lives with care recipient	105 (77%)
Age, mean (SD)	60 (27–86)
Gender, female	116 (85%)
Education, college or graduate degree	121 (89%)
Employment, retired/not employed	75 (55%)
Has some medical training	31 (23%)
Race: Asian	4 (3%)
African American	20 (15%)
White	112 (82%)
Self-rated physical health:	

Characteristics of the Person with Dementia	N (%) or Mean (range)
very good or excellent	86 (63%)
good	38 (28%)
poor or fair	12 (9%)

^a Minimum Data Set Cognitive Performance Scale;¹⁵ scores 0–1 = mild, 2–3 = moderate, 4–6 = severe.

^b Other included 5 sons, 1 sister, 1 great niece, 1 mother, 3 partners, 1 partner-in-law, and 1 stepdaughter.

Table 2

Six-Month Incidence of New or Worsening Symptoms among Persons with Dementia Living at Home (N = 136), Overall and by Dementia Severity

Symptom or Symptom Category	Number (%) of Caregivers Reporting, by Severity of Care Recipient Dementia			P-Value for Difference
	Total N=136	Mild/Moderate N=92	Severe N=44	
Organ-Specific Symptoms/Signs				
Any Organ-specific Symptom	122 (90)	81 (88)	41 (93)	.55
Voice and Speaking Problems	62 (46)	36 (39)	25 (57)	.05
Urinary Incontinence	44 (32)	29 (32)	15 (34)	.76
Skin Injuries	37 (27)	22 (24)	15 (34)	.011
Constipation	33 (24)	15 (16)	18 (41)	.002 *
Cough	27 (20)	17 (19)	10 (23)	.56
Urinary Tract Infection	24 (18)	13 (14)	11 (25)	.12
Abdominal Pain	23 (17)	12 (13)	11 (25)	.08
Dental Problems	23 (17)	12 (13)	11 (25)	.08
Vision Problems	23 (17)	16 (17)	7 (16)	.99
Hearing Loss	22 (16)	18 (20)	4 (9)	.14
Blood Pressure	20 (15)	10 (11)	10 (23)	.07
Breathing Problems	19 (14)	11 (12)	8 (18)	.33
Diarrhea	19 (14)	14 (15)	5 (11)	.54
Leg Swelling	14 (10)	10 (11)	4 (9)	.95
Red or Swollen Eye	13 (10)	10 (11)	3 (7)	.55
Pressure Ulcers	12 (9)	4 (4)	8 (18)	.019 *
Pain with Urination	10 (7)	8 (9)	2 (5)	.50
Other Organ-specific Symptoms ^a	37 (27)	24 (26)	13 (30)	.67
Behavioral Symptoms/Signs				
Any behavioral symptom	121 (89)	82 (89)	39 (89)	.93
Active behaviors ^b	93 (68)	62 (67)	31 (71)	.72
Passive behaviors ^c	108 (79)	73 (79)	35 (80)	.98
Worsening Confusion	101 (74)	71 (77)	30 (68)	.26
Agitation	77 (57)	51 (55)	26 (59)	.69
Hallucinations/Delusions	61 (45)	38 (41)	23 (52)	.23
Stress and Anxiety	56 (41)	41 (45)	15 (34)	.56
Aggression	49 (36)	34 (37)	15 (34)	.75
Depression	44 (32)	28 (30)	16 (36)	.49
Resisting Care	44 (32)	32 (35)	12 (27)	.38
Hoarding and Hiding	34 (25)	27 (29)	7 (16)	.09
Wandering	30 (22)	20 (22)	10 (23)	.99

Symptom or Symptom Category	Number (%) of Caregivers Reporting, by Severity of Care Recipient Dementia			P-Value for Difference
	Total N=136	Mild/Moderate N=92	Severe N=44	
New or Different Sexual Behavior	7 (5)	6 (7)	1 (2)	.29
Nonspecific Symptoms/Signs				
Any Nonspecific Symptom	120 (88)	81 (88)	39 (89)	.92
Decreased Activity	87 (64)	54 (59)	33 (75)	.06
Not Eating or Drinking	60 (44)	41 (45)	19 (43)	.88
Falls	47 (35)	34 (37)	13 (30)	.40
Not Taking Care of Self	48 (35)	33 (36)	15 (34)	.84
leep Problems (Nighttime)	45 (33)	29 (32)	16 (36)	.58
Chewing and Swallowing Problems	41 (30)	24 (26)	17 (39)	.14
Sleep Problems (Daytime)	38 (28)	24 (26)	14 (32)	.49
Fever	16 (12)	8 (9)	8 (18)	.15
Suspected Abuse or Neglect	6 (4)	4 (4)	2 (5)	.96

* Accepted as a true finding using a false discovery rate of .05 as defined by Benjamini and Hochberg.²⁶

^a Includes the following symptoms, each of was reported at least once: chest pain, diabetes, head injury, passing out, vomiting, blood in the urine, nosebleeds, and hip fracture.

^b Active behaviors include agitation, aggression, resisting care, wandering, and hiding or hoarding.

^c Passive behaviors include decreased activity, not eating or drinking, and not taking care of self.

Table 3

Six-Month Incidence of New or Worsening Symptoms among Persons with Dementia Living at Home (N = 136), and Association between Symptom Incidence and Incidence of Acute Medical Care Use (Hospitalization or Emergency Department Visit)

Symptom or Symptom Category	Number (%) of Caregivers Reporting	Association with Hospitalization or ED Visit	
		Odds Ratio	P-Value
Organ-Specific Symptoms/Signs			
Any Organ-specific Symptom	122 (90)	3.17	.023
Voice and Speaking Problems	62 (46)	2.33	.010 *
Urinary Incontinence	44 (32)	1.74	.13
Skin Injuries	38 (28)	3.49	.001 *
Constipation	33 (24)	2.23	.039
Cough	27 (20)	1.15	.77
Urinary Tract Infection	25 (18)	3.47	.006 *
Abdominal Pain	23 (17)	2.00	.15
Dental Problems	23 (17)	1.33	.44
Vision Problems	23 (17)	0.78	.64
Hearing Loss	22 (16)	0.47	.24
Blood Pressure	20 (15)	7.07	<.001 *
Breathing Problems	19 (14)	1.58	.24
Diarrhea	19 (14)	1.83	.23
Leg Swelling	15 (11)	0.80	.74
Red or Swollen Eye	13 (10)	1.52	.64
Pressure Ulcers	12 (9)	4.48	.007 *
Pain with Urination	10 (7)	1.56	.54
Other Organ-specific Symptoms ^a	37 (27)	2.01	.001 *
Behavioral Symptoms/Signs			
Any behavioral symptom	121 (89)	1.44	.38
Active behaviors ^b	109 (80)	1.45	.26
Passive behaviors ^c	93 (68)	1.19	.60
Worsening Confusion	101 (74)	1.02	.95
Agitation	78 (57)	1.57	.16
Hallucinations/Delusions	62 (46)	3.72	<.001 *
Stress and Anxiety	57 (42)	1.81	.08
Aggression	50 (37)	1.54	.22
Depression	44 (32)	2.32	.017
Resisting Care	44 (32)	1.18	.66
Hoarding and Hiding	35 (26)	1.35	.46
Wandering	30 (22)	1.64	.23
New or Different Sexual Behavior	7 (5)	0.68	.73
Nonspecific Symptoms/Signs			

<u>Symptom or Symptom Category</u>	Number (%) of Caregivers Reporting	<u>Association with Hospitalization or ED Visit</u>	
		Odds Ratio	P-Value
Any Nonspecific Symptom	120 (88)	2.08	0.10
Decreased Activity	89 (65)	1.90	.047
Not Eating or Drinking	60 (44)	1.35	.38
Falls	49 (36)	3.20	.001 *
Not Taking Care of Self	49 (36)	1.65	.16
Sleep Problems (Nighttime)	45 (33)	2.40	.014
Chewing and Swallowing Problems	41 (30)	1.36	.44
Sleep Problems (Daytime)	38 (28)	1.61	.23
Fever	16 (12)	2.70	.06
Suspected Abuse or Neglect	6 (4)	0.67	.72

* Accepted as a true finding, assuming a false discovery rate of 0.05 as defined by Benjamini and Hochberg.²⁶

^a Includes the following symptoms, each of was reported at least once: chest pain, diabetes, head injury, passing out, vomiting, blood in the urine, nosebleeds, and hip fracture.

^b Active behaviors include agitation, aggression, resisting care, wandering, and hiding or hoarding.

^c Passive behaviors include decreased activity, not eating or drinking, and not taking care of self.