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Dementia-related restlessness: relationship to characteristics of persons with dementia and family caregivers

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Abstract

Objective: Dementia-related restlessness is commonly endorsed by caregivers but not well understood. This study examines differences in characteristics (demographics, cognitive status, physical function, pain, and mood) of persons with dementia whose caregivers endorse restlessness versus those who do not. We also examine the relationship of restlessness to caregiver well-being including burden, upset with behaviors, mastery, and depressive symptomatology.

Methods: We combined baseline data from three caregiver intervention studies of community-dwelling persons with dementia who exhibited neuropsychiatric symptoms ($n = 569$) as measured by the Agitated Behaviors in Dementia Scale. We conducted bivariate correlations and independent t-tests by using the Agitated Behaviors in Dementia Scale restlessness item.

Results: Nearly 65% ($n = 367$) of dementia caregivers reported restlessness. There were no significant differences between those with and without ($n = 202$) reported restlessness concerning functional status (physical or cognitive). However, persons with restlessness had significantly higher pain scores ($p < 0.01$), were more likely to be on behavioral medications ($p < 0.001$), and had more neuropsychiatric symptoms as compared with persons without restlessness ($M = 11.11$, nonrestless; $M = 6.61$, restless) (p < 0.001). Caregivers of persons with dementia-related restlessness reported greater burden ($p < 0.001$), behavioral upset ($p < 0.001$), depression ($p < 0.001$), and lower mastery providing care ($p < 0.01$) compared with caregivers of persons without dementia-related restlessness.

Conclusions: Restlessness is a common neuropsychiatric symptom that appears to be associated with poorer functioning in persons with dementia and greater distress in their caregivers. Further research is needed to understand the unique contributions of restlessness to care burden and quality of life of persons with dementia, as well as ways to address this distressing symptom.

Keywords

restlessness; neuropsychiatric symptoms; dementia; behaviors; caregiver

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Conflict of interest
None declared.

Introduction

Neuropsychiatric symptoms are a common feature of dementia for the nearly 47 million people worldwide who have this disorder (Alzheimer's Disease International, 2015). Also referred to as behavioral symptoms or behavioral and psychological symptoms of dementia, neuropsychiatric symptoms (NPS) tend to worsen with dementia progression and are associated with negative sequelae including increased health care utilization, nursing home placement, and need for more advanced caregiving (Jutkowitz *et al.*, in press). Caregivers also find NPS one of the most challenging aspects of dementia care, resulting in increased upset and depression (de Vugt *et al.*, 2005; Allegri *et al.*, 2006; Lima-Silva *et al.*, 2015).

Although the presence of NPS is almost universal in persons with dementia at some point in the course of disease (Lyketsos *et al.*, 2002; Profenno *et al.*, 2005), each person may manifest a unique symptom profile. Restlessness is an NPS that occurs frequently and is cited as distressing by caregivers of persons with dementia (Regier and Gitlin, 2016). Emblematic of NPS, restlessness is often referred to as a form of agitation despite some evidence that it may be a distinct but co-occurring behavior (Algase *et al.*, 2007a; Algase *et al.*, 2007b). As restlessness is either ignored in NPS measures or grouped with other behaviors, typically agitation, its unique contribution to disease burden is unclear (Regier and Gitlin, 2016).

To begin to understand the specific contribution of restlessness to disease burden for both persons with dementia and their caregivers, this study evaluated whether there were differences in the sociodemographic and functional profiles of persons with dementia with and without restlessness. We also examined possible differences in caregiver profiles. We considered a range of factors based on our proposed definition of restlessness as consisting of three key attributes: diffuse motor activity or motion subject to limited control, nonproductive or disorganized behavior, and subjective distress. Restlessness should be differentiated from and not confused with wandering or elopement, pharmacological side effects, a mental or movement disorder, or behaviors occurring in the context of a delirium or at end of life (Regier and Gitlin, 2016).

With this definition in mind, we examined demographic characteristics, cognitive and physical functioning of persons with dementia, and caregiver well-being to derive a profile of families managing restlessness. As this is an exploratory study, we did not have a priori hypotheses and viewed this study as a first step in understanding the potential impact of dementia-related restlessness on families.

Method

This secondary data analysis combined the baseline data from three randomized controlled trials conducted by one of the authors (LNG): (i) New Ways for Better Days: Tailoring Activities Program (*n* = 60; Gitlin *et al.*, 2008), a home-based intervention in which occupational therapists trained in the protocol develop activities tailored to the interests and capabilities of persons with dementia and train caregivers in incorporating these activities into daily care routines; (ii) Advancing Caregiving Techniques Project (*n* = 272; Gitlin *et al.*, 2007), which tests the effectiveness of a nonpharmacological home-based intervention to reduce behavioral and psychological symptoms of dementia and caregiver distress; and (iii) Challenging Outdoor Personal Experience Project (n = 209; Gitlin *et al.*, 2010), a nonpharmacological, biobehavioral approach to support daily function and quality of life for persons with dementia and the well-being of their caregivers. The combined data used in this study were collected at the initial (baseline) interview, prior to randomization and implementation of an intervention. This study was approved by the Institutional Review Board at the principal investigator's (LNG) institution.

Participants

Participants were 569 Philadelphia-area caregivers of persons with moderate-stage dementia with one or more behavioral disturbances. Inclusion criteria for persons with dementia across all three trials included being English-speaking, having a physician's diagnosis of dementia or Mini Mental State Examination (MMSE; Folstein *et al.*, 1975) of ≤23, and able to feed self and participate in at least two self-care activities. Exclusion criteria across all three trials were a diagnosis of schizophrenia, bipolar disorder, dementia due to head trauma, bed-bound condition, MMSE of zero, or nonresponsiveness (i.e., unable to respond to short commands). Caregivers were English-speaking, at least 21 years of age, lived with the person with dementia, provided at least 4 h of daily care, and reported that the person with dementia exhibited boredom, sadness, anxiety, agitation, restlessness, or difficulty focusing on a task. Caregivers involved in another study, seeking nursing home placement within the timeframe of the trial, terminally ill, in active cancer treatment, or with three or more hospitalizations in the past year were excluded. Additional recruitment and procedural details for each trial are described elsewhere (Gitlin *et al.*, 2007; Gitlin *et al.*, 2008; Gitlin *et al.*, 2010).

Study variables

Factors related to persons with dementia.

Neuropsychiatric symptoms.: For all three trials (Tailoring Activities Program, Advancing Caregiving Techniques Project, and Challenging Outdoor Personal Experience Project), the caregivers reported behavioral symptoms at baseline (prior to randomization and receipt of interventions) via the 16-item Agitated Behaviors in Dementia Scale (ABID; Logsdon *et al.*, 1999). For each behavior, the caregivers indicated occurrence (yes or no) and frequency in past month. For this study, we calculated the number of NPS occurring (α = 0.86 for total sample). For restlessness, we used a single item from the ABID which defined restless-type behavior as "restlessness, fidgetiness, or inability to sit still (yes/no)."

Functional capacity.: For functional dependence, we used a 15-item measure, Caregiver Assessment of Function and Upset, previously proven to be psychometrically sound and corresponding to objective determinations of dependence and assistance required (Gitlin *et al.*, 2005). Items included eight instrumental activities of daily living (IADL; telephone, shopping, meal preparation, housework, laundry, travel, medicine, and managing finances) and seven self-care activities of daily living (ADL; bathing, dressing upper/lower body, toileting, grooming, eating, and getting in/out of bed). For each item, the caregivers indicated whether the persons with dementia were completely independent (score = 7); if there was a safety concern, excessive time required, or assistive devices used (score = 6); if supervision was needed (setup and cueing) but no physical help provided (score = 5); or physical help (4 = a little, 25% assistance, 3 = moderate, 50% assistance, 2 = a lot, 75% assistance, or 1 = complete help, and >75% assistance) was needed. A total mean functional dependence score was derived by summing across items and dividing by number of items (actual range of means = 1.02−6.3). Lower scores represented greater dependence (α = 0.92). Subscale scores for IADL (α = 0.81) and ADL (α = 0.93) dependence were similarly derived for the total sample.

Cognition.: Cognition was assessed via the widely used MMSE (Folstein *et al.*, 1975), a 30-item screening tool that briefly assesses the domains of orientation, memory, attention, visuospatial skills, and language. Research shows that the cutoff score of 24 provides a reliable diagnosis of dementia with high sensitivity, specificity, and diagnostic values (Stuss *et al.*, 1996).

Pain.: Using a five-point Likert scale ranging from 1 (“not at all”) to 5 (“extremely”), the caregivers reported the degree of pain experienced by the person with dementia (1) over the past few weeks, (2) at the present time, (3) when pain is at its worst, and (4) how much pain or physical discomfort interferes with his or her day-to-day activities. In the present sample, the internal consistency was α = 0.90.

Factors related to family caregivers.

Burden.: Subjective burden was measured as upset with behaviors (Roth *et al.*, 2003; 0 = not upset to 10 = extremely upset, with a total target score from 0 to 40 derived by summing across the upset responses for up to four behaviors identified as most distressful) and the 12-item Zarit Burden Interview Short Form (Bédard *et al.*, 2001; 0 = never to 4 = nearly always), with the sum total used in analyses (α = 0.89).

Depression.: Caregiver depression was measured by the 20-item Center for Epidemiologic Studies Depression Scale (Radloff, 1977), with symptoms rated as occurring in the past week (0 = less than 1 day to 3 = 5−7 days). Scores represented the mean of the summed responses, with higher scores indicating greater symptomatology (α = 0.91).

Mastery.: Caregiver mastery, conceptualized as a subjective self-appraisal by the caregiver of how he or she responds to the person with dementia’s demands and executes the processes of caregiving (Lawton *et al.*, 1989), was measured by a five-item Likert scale (1 = never to 5 = always) (α = 0.70).

Data analysis

Frequencies of overall NPS were obtained. Sociodemographic and functional characteristics of caregivers and persons with dementia were examined and compared in the context of presence or absence of restlessness. Between-group differences for all characteristics were assessed by using independent t-tests. Bivariate correlations among NPS were measured with the Pearson product-moment two-tailed correlation coefficient analysis.

Results

Sample characteristics

As shown in Table 1, for the total sample, persons with dementia were predominantly female (61%), Caucasian (72%), married or partnered (50%), and had a mean age of 82.3 years (SD = 8.68). On average, persons with dementia required complete-to-substantial assistance with instrumental activities of daily living and moderate assistance with self-care activities. The mean score on the pain scale was 9.92 (SD = 4.21), indicating little-to-moderate pain over the past few weeks, currently, at their worst, and while attempting daily activities. The mean MMSE was 12.92 (SD = 8.09), suggesting moderate-to-severe cognitive impairment.

The caregivers were primarily female (75%), Caucasian (72%), married or partnered (69%), and retired or unemployed (64%). One third of the caregivers had attended some college (30%) and reported good (32%) or very good health (31%). The mean caregiver age was 65.2 years (SD = 12.31). On average, the caregivers had provided care for nearly 4 years. Forty-six percent of the participants were spousal caregivers. The caregivers had a mean depressive symptom score of 8.97 (SD = 5.67), indicating that most did not report depressive symptoms. However, 71.4% of caregivers had a score of >16, suggestive of clinical meaningful symptomatology (Bédard *et al*., 2001). The caregivers also reported, on average, clinically significant burden on the Zarit Burden Interview Short Form (Table 1).

Frequency of restlessness and other neuropsychiatric symptoms

Dementia-related restlessness of persons with dementia was endorsed by nearly 65% (N = 367) of dementia caregivers (Table 2). Restlessness was the fourth most prevalent NPS, preceded by repetitive questioning (79%), arguing (67%), and anxiety (67%).

Restlessness was significantly correlated with all other NPS on the ABID ($p < 0.05$), with the exception of inappropriate sexual behavior ($p > 0.05$). For those with restlessness, it appeared to co-occur with each of the other 15 NPS, and most frequently with arguing, anxiety, and agitation (Table 3). There were only three persons with dementia (17%) whose caregivers endorsed restlessness as his or her sole NPS.

Characteristics associated with restlessness in persons with dementia

Persons with dementia-related restlessness ($n = 367$) were more likely to be widowed and less likely to be married/partnered than persons without restlessness ($n = 202$; $t_{(567)} = -1.984$, $p < 0.05$), have greater pain ($t_{(566)} = -3.018$, $p < 0.01$), exhibit more NPS overall (restless $M = 11.11$, nonrestless $M = 6.61$) ($t_{(567)} = -15.047$, $p < 0.001$), and were more likely to be prescribed medications to manage challenging behaviors ($t_{(567)} = -4.429$, $p < 0.001$). Persons with dementia-related restlessness were statistically significantly more likely to be prescribed medications for memory impairment compared with those without restlessness ($t_{(565)} = 3.119$, $p < 0.01$). However, the likelihood of persons with restlessness taking pain medications compared with persons without restless ness was not statistically significant ($t_{(567)} = -1.959$, $p = 0.051$). Gender, race, functional independence (i.e., IADLs/ADLs), and prescription of depression medications were not significantly related to restlessness (Table 1).

Caregiver characteristics associated with restlessness

The caregivers of persons with dementia-related restlessness were significantly younger ($t_{(566)} = 3.678$, $p < 0.001$) and more likely to be female ($t_{(567)} = 3.342$, $p < 0.001$) than the caregivers of persons who were not restless (Table 1). The caregivers of this group also reported statistically significantly more burden ($t_{(566)} = -5.097$, $p < 0.001$), higher degree of upset with dementia behaviors ($t_{(567)} = -4.009$, $p < 0.001$), lower sense of mastery in managing behaviors ($t_{(567)} = 3.375$, $p < 0.01$), and greater depressive symptomatology ($t_{(566)} = -4.231$, $p < 0.001$) than their counterparts not reporting restlessness. Caregiver race, marital status, level of education, self-rated health, and number of years providing care were not significantly associated with restlessness.

Discussion

In this exploratory study of community-living families, we found that most dementia caregivers reported the occurrence of restlessness. This behavior significantly co-occurred with all other NPS as measured by 23 behavioral items except for one (inappropriate sexual behavior), indicating that restlessness seldom occurs alone. Restlessness appears to occur most frequently with other types of agitated behavior such as arguing, anxiety, and agitation (Table 3). This co-occurrence of restlessness suggests that it is a form of agitation but also distinct, thus presenting notable challenges toward identifying its unique effects on persons with dementia. Nevertheless, there appear to be differences between those with and without restless behaviors. These differences indicate that restlessness appears to impact both persons with dementia and their caregivers negatively and in different areas of functioning and well-being.

It is important to note the characteristics of persons with dementia that were not associated with the presence of restlessness. Regarding persons with dementia, we found that restlessness was not statistically significantly associated with sociodemographic characteristics including age, gender, and race/ethnicity nor was it associated with cognitive and physical functioning. Thus, restlessness was reported for individuals with a range of levels of functioning such that cognition and physical function are not differentiating factors of this particular NPS. However, restlessness was significantly associated with behavioral characteristics such that this group had higher pain, was prescribed more behavioral medications, and had a greater number of NPS overall.

Several potential explanations may account for these findings. First, similar to mental disorders which often co-occur such as depression and anxiety, there may be a common underlying pathophysiology for restlessness and other related but distinct NPS. For example, corticotropin-releasing factor is a peptide implicated in the pathophysiology of both anxiety and depression, suggesting that these mental disorders share a common neuroendocrinological dysregulation (Boyer, 2000). Similarly, restlessness and its comorbidities may manifest due to modifications or dysregulation in a specific neurobiological system, such as the brain's cholinergic, noradrenergic, serotonergic, and dopaminergic neurotransmitters (Raskind and Peskind, 1994; Cummings and Beck, 1998; Garand and Hall, 2000). Thus, it is possible that restlessness and other NPS often lumped together as “agitation” exist within a neurobiological continuum related to one or more of these neurotransmitters.

Second, it is possible that there is a temporal order of NPS, wherein restlessness sets the stage for vulnerability and, if not addressed, can lead to the expression of other behaviors such as agitation. In other words, restlessness may precede the development of other NPS on the aforementioned continuum. Others have noted a temporal ordering of behavioral occurrences as well. For example, Woods, Rapp, and Beck (2004) found that episodes of aggression and violence often followed initial episodes of agitation. As ours was a cross-sectional study, it is not possible to discern a timeline or sequence by which behaviors manifested. Future research is needed to examine the processes by which restlessness occurs in persons with dementia, motorically or otherwise. Importantly, the presence of a shared pathophysiological mechanism underlying neurotransmitter dysregulation in restlessness and its comorbidities could broaden the range of pharmacological and nonpharmacological treatment options and prevent the occurrence of NPS and, specifically, restlessness.

As to caregivers, we found that sociodemographic characteristics (gender, age, race/ethnicity, and relationship of caregiver to person with dementia) were not associated with the occurrence of restlessness. However, restlessness was associated with negative psychosocial factors including high burden, depression, and upset with NPS compared with caregivers of persons with dementia without restlessness. Furthermore, caregivers reporting restlessness also endorsed feeling less capable and competent in terms of dealing with NPS. This is disconcerting, as restlessness is often ignored in behavioral measures or grouped with other behaviors, resulting in missed opportunities for detection, assessment, and intervention, particularly as it concerns caregiver education and problem-solving strategies to alleviate this behavioral symptom (van der Linde *et al.*, 2014). It may be that the presence of restlessness along with other NPS reflects a tipping point for caregivers, providing excessive disease burden. Our findings suggest that restlessness is associated with greater distress and, as such, there is need for its more accurate assessment and identification.

As this study involved secondary analysis, we were dependent upon the measures of behaviors used in the three combined intervention studies. Specifically, the ABID includes only a single item for restlessness, which may not capture the complexities of this behavior type. However, there is no adequate multidimensional instrument available to measure dementia-related restlessness (Gitlin *et al.*, 2014; Regier and Gitlin, 2016). Nevertheless, even with this single item, we show distress associated with the presence of restlessness among other co-occurring behaviors on persons with dementia and their caregivers by using a commonly-used available measure.

Another possible limitation is that the two groups (restless vs. nonrestless) were developed post hoc, which makes it difficult to control for various factors, and we do not know with certainty if it is restlessness or another behavior that may be shared in one group versus the other. There may be a latent variable that differentiates the two groups that was not measured, and our findings must therefore be considered exploratory. Furthermore, as a cross-sectional study, it was not possible to observe trends over time, sequencing of the occurrences of behaviors or to follow participants longitudinally to observe when and how restlessness emerged.

In summary, restlessness is an NPS that was linked in this study to negative factors for persons with dementia and caregivers. It appears that the presence of this particular NPS may reflect a tipping point for caregivers, making it particularly troublesome and difficult to manage. Our findings suggest that restlessness should not be subsumed or categorized under other behaviors such as agitation as its presence may have unique effects on families. More research is needed to understand its phenotype in order to adequately assess and intervene with this behavior. This study also shows that it is difficult to disentangle behaviors as they appear to co-occur and have yet to be adequately described. Finally, these findings underscore the need for further refinement of the conceptual and operational definition of dementia-related restlessness so that interventions can be developed that target this NPS and can be accurately evaluated.

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Key points

- Restlessness has negative outcomes for both persons with dementia and their caregivers.
- Persons with dementia-related restlessness may be more vulnerable to other neuropsychiatric symptoms.
- Restlessness is poorly measured, and therefore, it is difficult to target this behavior with interventions and provide caregivers with much-needed support in managing restlessness.

Table 1

Sociodemographic and functional characteristics of persons with restlessness versus those without

Characteristics	**Full sample *n* = 569**	**Restless *n* = 367**	**Not restless *n* = 202**	***p*-value**
Person with dementia				
Age, mean (SD)	82.25 (8.68) ($R = 55.0–105.1$)	82.20(9.15) ($R = 55.0–105.1$)	82.42 (7.75) ($R = 57.2–101.5$)	0.737
Gender (%)				
Male	39.2	39.8	38.1	0.698
Female	60.8	60.2	61.9	
Race (%)				
White	71.9	70.6	74.3	0.595
African American	26.0	27.8	22.8	
Other	2.2	1.6	3.0	
Marital status (%)				**0.048**
Married or partnered	50.1	46.3	56.9	
Widowed	40.1	43.1	34.7	
Divorced	7.6	8.2	6.4	
Single, never married	2.3	2.5	2.0	
IADL, mean (SD)	1.60 (0.68)	1.58 (0.69)	1.63 (0.67)	0.492
ADL, mean (SD)	3.13(1.19)	3.19(1.18)	3.01 (1.20)	0.173
Pain in past (%)				0.079
Not at all	23.9	19.9	31.2	
A little	30.6	32.7	26.7	
Moderately	20.6	22.1	17.8	
Quite a bit	20.9	20.7	21.3	
Extremely	3.7	4.1	3.0	
Pain score, mean (SD)	9.92 (4.21)	10.31 (4.09)	9.20 (4.35)	**0.003**
MMSE, mean (SD)	12.92 (8.09)	12.85 (8.05)	13.04 (8.17)	0.799
Memory medication (%)	72.9	68.9	80.2	**0.002**
Pain medication (%)	40.1	43.1	34.7	0.051
No. of behaviors, mean (SD)	9.51 (4.03)	11.11 (3.55)	6.61 (3.14)	**0.000**
Total no. of behaviors	5412	4076	1336	**0.000**

Characteristics	**Full sample *n* = 569**	**Restless *n* = 367**	**Not restless *n* = 202**	***p*-value**
Behavioral medication (%)	32.9	39.2	21.3	**0.000**
Depression medication (%)	39.9	41.7	36.6	0.239
Caregiver				
Age, mean (SD)	65.2 (12.31)	63.8(12.22)	67.7(12.11)	**0.000**
Gender (%)				**0.001**
Male	24.6	20.2	32.7	
Female	75.4	79.8	67.3	
Race (%)				0.320
White	71.7	70.3	74.3	
African American	26.0	27.2	23.8	
Other	2.3	2.5	2.0	
Marital status (%)				
Married or partnered	68.5	66.8	71.8	0.252
Widowed	3.3	3.8	2.5	
Divorced	13.4	16.1	12.9	
Single, never married	13.2	13.4	12.9	
Education (%)				0.216
>HS	5.6	4.9	6.9	
HS	26.5	26.4	26.7	
Some college	30.2	31.3	28.2	
College degree	22.1	20.2	25.7	
Graduate degree	15.3	17.2	11.9	
Employed (%)	35.7	40.9	26.2	**0.000**
Self-rated health (%)				0.132
Poor	4.4	4.4	4.5	
Fair	19.7	20.4	18.3	
Good	31.6	31.9	31.2	
Very good	30.6	33.0	26.2	
Excellent	13.7	10.4	19.8	
Relationship to person with dementia (PwD)				0.589
Spouse	45.7	42.3	52.0	

Characteristics	**Full sample *n* = 569**	**Restless *n* = 367**	**Not restless *n* = 202**	***p*-value**
Nonspouse	54.5	57.9	48.1	
Years caregiving, mean (SD)	3.81 (3.35)	3.80 (3.53)	3.84 (2.99)	0.897
Burden score, mean (SD)	22.29 (9.66)	23.79 (9.40)	19.56 (9.54)	**0.000**
Behavioral upset, mean (SD)	4.14(2.44)	4.44(2.41)	3.59 (2.41)	**0.000**
Mastery, mean (SD)	2.90 (.61)	2.84 (.62)	3.02 (.58)	**0.001**
CESD score, mean (SD)	8.97 (5.67)	9.70 (5.74)	7.63 (5.30)	**0.000**

Note: Bold *p*-values indicate statistical significance of independent *t*-test.

Table 2

Frequency of neuropsychiatric symptoms

Behavior	Frequency (%)	*N*
Arguing	67.3	383
Anxiety	66.6	379
Restlessness	64.5	367
Verbal aggression	53.6	305
Rejection of care	53.1	302
Agitation	53.1	302
Waking caregiver	51.1	291
Delusions	37.8	225
Hallucinations	22.3	127
Crying out	21.6	123
Inappropriate social behavior	19.9	113
Wandering	18.3	104
Hurting self or others	16.2	92
Physical aggression	15.8	90
Destroying property	6.3	36
Inappropriate sexual behavior	3.9	22

Note: $n = 569$.

Table 3

Frequency of neuropsychiatric symptoms co-occurring with restlessness

Behavior	**Frequency (%)**	***n***
Arguing	75.5	277.1
Anxiety	74.4	273.0
Agitation	62.7	230.1
Rejection of care	61.3	225.0
Verbal aggression	60.2	220.9
Waking caregiver	59.4	218.0
Delusions	45.5	167.0
Hallucinations	27.0	99.1
Crying out	26.7	98.0
Wandering	24.5	89.9
Inappropriate social behavior	24.0	88.1
Hurting self or others	19.9	73.0
Physical aggression	18.5	67.9
Destroying property	8.7	31.9
Inappropriate sexual behavior	4.4	16.1

Note: $n = 367$.