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Feature Article

A pilot study: Resistive behavior in the context of informal caregiver-assisted activities of daily living☆

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ABSTRACT

Providing care for people with dementia is difficult when resistive behaviors displayed by people impede caregiving efforts. **Purpose:** To examined the frequency of resistive behaviors during informal caregiver-assisted activities of daily living and the impact of these occurrences. **Design:** A cross sectional design was used to recruit 17 caregivers from Alzheimer's support group meetings in 2010. **Method:** Self-report surveys were used to obtain participants' report of resistive behaviors. **Findings:** A positive correlation was found between caregivers reported frequency of bathing behaviors and their reported upset with dressing behaviors. Gender differences emerged in caregiver reported frequencies of the resistive behaviors. Caregivers reported behaviors occurring between two and six times per week but rated the not frequent behaviors as somewhat to very upsetting when they occurred. **Conclusions:** When informal caregivers provide assisted care, resistive behaviors occur. Future research is needed to identify interventions to help caregivers manage their upset when resistiveness occurs.

Background and significance

The most common form of dementia is Alzheimer's disease (AD), a debilitating condition that is characterized by impaired judgment, disorientation, confusion and behavioral changes. AD currently affects one in ten people 65 years of age and older with 82 percent of people with AD age 75 or older.[1] As the disease progresses, people with dementia invariably require assistance with activities that sustain life and well-being and reduce risks posed by inappropriate or potentially harmful behaviors. In the early stages of the disease, many require assistance with higher-level tasks, such as balancing a checkbook or safely preparing meals also known as Instrumental Activities of Daily Living (IADLs). As the disease progresses, assistance is required for more rudimentary functions of life such as bathing, dressing, and eating (also called activities of daily living or ADLs). Most often informal caregivers provide a significant portion of this much-needed assistance. Informal caregivers are defined as a relatives, partners, friends, or neighbors having a meaningful personal relationship and provides services without compensation.[2]

Providing care for people with dementia is often difficult and distressing to both professional caregivers and informal caregivers alike.[3] Not only do informal caregivers face the physical and emotional challenges of providing care, they must also handle the behavioral symptoms that often interfere with the delivery of care. As dementia attacks the person's capacity to process stimuli, interpret meaning, and respond in meaningful ways, care activities may be misunderstood or misinterpreted as a threat. In turn, care recipients may make attempts to withdraw or avoid what they believe to be impending harm. These behaviors often thwart the caregivers' delivery of needed assistance. Collectively, behaviors that interfere with the delivery of care are called *resistive behaviors*.[4] These behaviors have been described as physical, such as pushing or pulling away or verbal, such as verbally resisting or asking repetitive questions.[4,5]

Resistive behaviors occur not only in informal caregiving situations but formal caregiving as well. In studies of formal caregiver (i.e. paid caregivers) caring for people with AD in nursing homes, resistive behaviors have been documented primarily in the moderate to advanced stages of the disease.[4] There is little doubt that resistive behavior is problematic for formal caregivers. A rather robust body of research demonstrates the impact of resistive behaviors on formal caregiver's stress, nursing burnout, job turnover and increased cost of care.[6–8] Yet, the Alzheimer's Association[1] reports that family or friends are caring for the majority of people with dementia.

Family members or informal caregivers (friends) provide care for more than 90% of the people with AD.[1] This amounts to more people with AD being cared for by an informal caregiver than a formal caregiver. In doing so, informal caregivers of people with dementia have also reported experiencing the behavioral symptoms of the disease and report this as a major cause of burden.[9] The consequences of

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providing care for someone with dementia has been outlined in the stress process model developed by Pearlin et al.[10] Background and context of the caregiving experience (family composition, personal characteristics, and family networks) along with primary stressors (behaviors of the person with dementia such as resistive behaviors) are thought to contribute toward adverse health outcomes such as depression, anxiety, and overall decline in physical health. However, factor such as caregivers' social support systems and ways of coping with the memory-related behaviors that occur during caregiving may help to mediate the outcome responses to the primary stressor or memory-related behaviors.[10]

Further research findings linking problematic behaviors that interfere with the provision of care in the home to outcomes have identified that increased stress from primary stressors such as overload of the informal caregiver have resulted in an increased risk of institutionalization for the care recipient.[11,12] Although Mahoney and colleagues assert that resistive behaviors most often occur during bathing.[13] Rowe and colleagues found that 86% of the sample of community dwelling people with dementia exhibited disruptive behaviors without reference to the context of care.[4] More recently, informal caregivers' perceptions of their experiences with resistive behaviors during ADLs have been studied however; these researchers used secondary data analysis to examine the phenomenon.[14] There is little empirical support using primary data to specifically examine the incidence and informal caregivers' perceived significance of resistive behaviors during bathing, dressing, and eating (ADLs) for community dwelling people with dementia.

Purpose and research questions

The purpose of this pilot study was to obtain informal caregivers' prospective perceptions of the frequency of resistive behaviors during informal caregiver-assisted ADLs and the informal caregivers' perceived impact of these occurrences when assisting people with AD or dementia. The findings from this exploratory pilot study were also used to determine the feasibility of recruiting informal caregivers from Alzheimer's support group meetings for future investigations with informal caregivers caring for people diagnosed with dementia. The research questions guiding this inquiry were:

1. What is the frequency of the occurrence of resistive behaviors during informal caregiver-assisted bathing, dressing, and eating for people with dementia?
2. How upsetting are occurrences of resistive behaviors to informal caregivers of people with dementia?
3. What is the association between the frequency of occurrences of resistive behaviors during bathing, dressing, and eating and the caregivers' reported level of being upset when these behaviors occur?

Hypothesis. As the frequency of the behaviors increases the level of caregiver upset with the behavior will also increase during bathing, dressing, and eating.

Methods

Research design

Using the stress process conceptual model[10] a quantitative, cross sectional design was developed for this study to ascertain how the frequency of resistive behaviors impact family caregivers' perceptions of resistive behaviors. Data were collected at one point in time to obtain family caregiver's perceptions of the frequency as well as their level of upset with resistive behaviors that occur over the past week during informal caregiver-assisted eating, bathing and dressing. A cross-sectional design was chosen because of the practicality and economic feasibility of securing a sample for this pilot study.

Subjects and setting

Following an academic institutional review board approval, the subjects were recruited through Alzheimer's support group meetings from three neighboring geographical regions in a rural community between fall of 2009 and spring of 2010. A total of thirty-six informal caregivers were present at 5 different Alzheimer's support groups over a period of 6 months (15-scheduled support group meeting times) in a rural community. From those in attendance, 18 informal caregivers (50%) agreed to participate in the study. One of the informal caregivers declined to participate after initial verbal agreement. The declining caregiver stated that the care recipient did not display the behaviors of interest for the study. This resulted in 17 consenting participants.

For this study an informal caregiver was defined as an unpaid family member or friend who provides assistance or supportive care to person with a form of dementia (AD or other type). Informal caregivers were also required to be 18 years of age or older, understand the English language, provide some assistance with ADLs, and have experienced resistive behaviors. In addition, the care recipient was required to have a diagnosis of either dementia or AD. Caregivers' proxy reports of a diagnosis of dementia or AD were accepted as sufficient evidence of the disease.

Demographic information pertaining to the caregivers included: gender and age, their relationship with the care recipient, the amount of time the caregivers perceived to be in a caregiving role, living arrangements between caregivers and care recipients, and amount of time spent caring for the care recipients. In addition, informal caregivers reported information pertaining to the care recipients, which included: gender, age, time since the care recipient was diagnosed with dementia or Alzheimer's disease.

The majority of informal caregivers (76%) were female with an average age of 68 (range of 50–80). Informal caregivers had been providing care for someone with dementia for an average of four years (range of less than one year to 16 years) and the majority of caregivers (64.7%) were the spouses of the care recipient. More than half (59%) of informal caregivers lived with their care recipient. Informal caregivers reported that just over half (53%) of the persons with dementia were female and that they had been providing care on average of almost five years (range 1–16 years) since a diagnosis of dementia. These demographics are similar to the current demographics of informal caregivers caring for people with dementia (Alzheimer's Association, 2017). Additional characteristics of the 17 consenting family caregiver participants and informal caregivers' report of the persons they cared for are displayed in Table 1 and Table 1b.

Data collection

At the regularly scheduled Alzheimer's support group meetings, the support group leader introduced the first author and caregivers were asked informal caregivers if the first author could sit through the caregiver support group meeting with them. There were no

Table 1
Caregiver and Caregivers' report of care recipient demographics.

Demographics	Caregiver	Recipient with dementia
Gender	13 (76%) Female	9 (53%) Female
Relationship	• 11 (64.7%) spouses • 6 (35.2%) children	• 11 (64.7%) spouses • 6 (35.2%) parents
Residence	• 10 (59%) lived with the person with dementia	• 7 (41%) did not live with the caregiver

Table 1b
Caregiver and Caregivers' report of care recipient demographics statistics.

Descriptive Statistics	N	Minimum	Maximum	Mean	St. Deviation
Caregiver Age	17	50	82	66.24	10.797
Years as a caregiver	17	0.30	16	3.90	3.64
Hours providing care per day	9	0.9	24	12.54	11.33
Years since Dementia diagnosis	15	1	16	4.7	4.03
Age of person with dementia	17	63	93	79.9	8.57

objections raised by caregivers and the first author joined the group. At the end of the support group meeting a brief overview of the project was given orally to group members by the first author and informal caregivers interested in the study were encouraged to remain and have their questions answered. Uninterested caregivers left the meeting at this time.

Informal caregivers who believed they had experienced the phenomenon of interest and wanted to participate completed a demographic data and survey providing information about their subjective experiences with resistive behaviors. By completing the forms informal caregivers were aware that they were providing implied consent. A modified subset of six items from the WRB tool[14] was reviewed with potential caregivers and instructions for completion was provided. Caregivers were asked to consider the preceding week's interactions with the care recipient during bathing, dressing and eating (ADLs) and document their perceptions of these events. Informal caregivers were required to rate the frequency of behaviors they experienced over the past week. A Likert-scale style rating was used with potential responses of two times per week, three to six times per week, one to two times per day, and many times per day. Caregivers were also asked to rate their level of being upset with the behaviors. These Likert-style ratings ranged from being "not at all to somewhat upset," "somewhat upset," "somewhat to very upset," to "very upset." Informal caregivers completed their weekly behaviors survey following the support group meeting. All completed data collection forms were coded for each participant and no identifiable information was obtained. After completing all forms, study participants were given a gift card as compensation for their time.

Instruments

The IRB reviewed the data collection tools for this study and approved the use of implied consent for increased confidentiality, as a consent form would have been the only identifiable source of participant information. Participants were given a written copy of the study summary, which included the researcher's contact information. All participants completed their own surveys. Data were collected using a brief demographic survey and a subset (six items) of the Weekly Record of Behaviors (WRB) Scale[14] to determine the frequency of behaviors during the contexts of assisted bathing, dressing and eating as well as the perceived level of upset during the three contexts. The WRB tool is a self report log using a Likert scale to measure the frequency of care recipient behaviors over the past week, an approximation of the duration of the resistive behavior and extent of distress perceived by the caregiver.[15] This measure includes ratings of 40 negative and 4 positive behaviors. For this study, only a subset of six items was used from the WRB as other items in the WRB did not pertain to the current study's research questions. This subset (6-item survey of WRB) has been used successfully in previous other research[14] and has an internal consistency (Cronbauch's alpha) coefficient of 0.53, which indicates only moderate inter-correlations.[14] However, previous researchers explained that the 6-item subset scale measures cumulative exposure to events and care recipients who display behaviors in one context (i.e. bathing) were not expected to necessarily display behaviors in the other contexts (i.e. dressing or eating) lending to a moderate inter-item correlation as acceptable in this circumstance.[14] These six items subset included behaviors such as struggling, refusing or resisting to bath, eat or dress; wearing inappropriate clothes, taking of clothes at inappropriate times; and having trouble sitting at the table containing the ADLs of interest for this study (eating, bathing, dressing). Caregivers reported the frequency of behaviors as well as their level of being upset during the contexts of eating, bathing, and dressing. Average scores were totaled for the level of upset and frequency of the six behaviors for each caregiver's report.

Data analysis

Data was analyzed using SPSS software (version 17.0). Descriptive statistics (frequencies and statistical mean differences with effect sizes) were used to answer the first two research questions and multiple regression analysis was used to answer the third research question investigating the relationship between the independent variable of frequency of behavior occurrences and the dependent variable of reported level of being upset with the behaviors while controlling for caregiver gender. Multiple regression allowed the researchers to examine the strength of the relationship between family caregivers' perceived levels of being upset with behaviors and the frequency of the behaviors displayed. It also provided the ability to predict the power of behavior frequency on caregivers' level of upset while controlling for caregiver gender and to test for variable interactions.

Results

Amount of care provided

Of the informal caregivers participating in the study, 82% reported providing either full or partial assistance during bathing, dressing, or eating. In fact, 30% of informal caregivers reported providing full assistance during either bathing, dressing or eating; 37% of caregivers reported providing partial assistance during either bathing, dressing or eating; and 31% of caregivers reported providing no assistance during bathing, dressing, or eating. Specifically, informal caregivers reported providing more complete care for bathing (47%) than dressing (24%) or eating (18%). Caregivers also reported more partial assistance was required for eating (53%) and dressing (42%) than bathing (24%). Nearly one third of informal caregivers reported no assistance was needed for either bathing (29%), dressing (35%) or eating (29%). Three informal caregivers (18%) reported no assistance needed for all three contexts (bathing, dressing, and eating) despite perceiving they had experienced resistive behaviors during assisted ADLs prior to the study.

Caregiver perceptions of care needed

The findings also revealed gender differences in caregivers' perceptions of the amount of assistance needed for bathing, dressing, and eating. For example, when caregiver gender was opposite to the care recipient gender (male caregiver and female care recipient or female caregiver and male care recipient), the caregiver reported care recipients needed more assistance on average with bathing (2.08) and dressing (2.08) than when the caregiver and care recipient were of the same gender (0.11 for bathing and 0.54 for dressing). However the opposite was true with assistance when eating. Caregivers' gender that matched the care recipient's gender (female caregiver and female care recipient) were more likely to report care recipients needing more assistance on average with eating (2.4) than caregivers whose gender was opposite that of the care recipient (1.5). These findings were further supported by effect sizes (ES) showing the medium to large differences (statistical significance) in perceived assistance needed for dressing (ES 0.54) and eating (ES −1.0) and for

Table 2
Average caregiver perception of assistance needed.

Caregivers' perceptions	Bathing	Dressing	Eating
Average matched*	2.0	1.6	2.4
Average mismatched **	2.1	2.1	1.5
Effect size	0.11	0.54	−1.0
Male caregivers	2.50	2.25	1.75
Female caregivers	1.92	1.85	1.77
Effect size	0.77	−0.45	0.02
Grand mean	2.06 (SD 0.75)	1.94 (SD 0.90)	1.76 (SD 0.90)

* Same gender caregiver and care recipient.
** Different gender caregiver and care recipient.

matched caregiver and care recipient gender compared with mismatched genders of caregiver and care recipient. The overall grand mean and standard deviation for each ADL is reported in Table 2.

Another gender difference with notable effect size was the differences in average amount of assistance reported by male caregivers compared to female caregivers for bathing and dressing. Male caregivers tended to report providing on average more assistance for bathing (2.5) and dressing (2.25) than female caregivers (1.9 and 1.8 respectively). The effect sizes for these differences were 0.77 for bathing and −0.45 for dressing showing large differences. However, both male caregivers and female caregivers perceived similar amounts of assistance provided for eating (1.75 and 1.77 respectively with small ES of 0.02).

Resistiveness during ADLs

The majority of informal caregivers reported experiencing resistive behaviors during the contexts of bathing, dressing, and eating. Six caregivers reported behaviors during bathing, five caregivers reported behaviors during dressing, and eleven caregivers reported behaviors during eating. Only six informal caregivers (35%) reported behaviors in all three contexts of bathing, dressing, and eating. Four caregivers (24%) reported experiencing behaviors during two of the three contexts and four other caregivers (24%) reported only experiencing behaviors in one of the three contexts. However, five of the seventeen caregivers (29%) reported assisting the care recipient during bathing, dressing, and eating but did not report any behaviors or upset during their caregiving encounters despite telling the first author that they had experienced resistive behaviors during assisted care.

Frequency of behaviors

The frequencies of behaviors were measured using ranges of occurrences on the 6-itme subset of the WRB tool.[14] These ranges included "2 times per week," "3–6 times per week," "1–2 times per day," and "many times per day".[14] Although caregivers could report behaviors as frequently as many times per day, the majority caregivers reported behaviors occurring between two to six times per week. In fact, of the caregivers reporting behaviors during eating, bathing, and/or dressing, 82% of eating behaviors, 83% of bathing behaviors, and 83% of dressing behaviors only occurred between two to six times per week. In contrast, only 9% of eating behaviors and 17% of bathing behaviors were reported by caregivers to occur as frequently as many times per day (See Table 3). Although the majority of informal caregivers reported the frequency of behaviors during assisted ADLs occurring only two to six times per week, their perceptions of being upset with these behaviors were notable.

Level of caregiver upset

The analysis of informal caregivers reporting their level of being upset showed that collectively informal caregivers reported either somewhat upset and somewhat to very upset for behaviors displayed during bathing (86%), dressing (100%), and eating (82%). In fact, all three contexts (bathing, dressing, and eating) appear to be stressful for informal caregivers when they experience resistive behaviors. No family caregiver reported being not at all upset with behaviors during the context of dressing. Lastly, there were a few caregivers (14%) who did report being, not at all upset with behaviors occurring during bathing and 18% reported not at all upset with behaviors during eating see Table 3.

Table 3
Frequencies of care recipient behaviors during eating, bathing, and dressing.

Behaviors	Eating ($N = 11$)	Bathing ($N = 7$)	Dressing ($N = 6$)
"2 Times" per week	45%	33%	50%
"3–6 Times" per week	36%	50%	33%
"1–2 Times" per day	9%	0	17%
"Many times" per day	9%	17%	0

Relationship between frequency and being upset

The hypothesis associated with the third research question was that family caregivers would perceive an increase in their level of being upset with the behaviors occurring during bathing dressing and eating as frequency of the behaviors increased and appeared to not be supported by the above descriptive findings. The majority of caregivers' reported the frequency of experienced behaviors (during bathing, dressing, and eating) to occur only two to six times per week and they reported the level of their upset when behaviors occurred to be somewhat to very upset. These findings appear not to support the hypothesis of this study. In order to answer the third research question a regression analysis was conducted to examine predictors of family caregivers' upset with behaviors displayed by people diagnosed with dementia during bathing, dressing, and eating. Because the above descriptive results also pointed to gender differences, two predictors were simultaneously entered into the model: family caregiver gender and frequency of the displayed behaviors. Together these predictors accounted for 26% (context of bathing), 36% (context of dressing), and 18% (context of eating) of the variance in family caregivers' upset with the behaviors. Family caregiver gender and frequency of behaviors were not statistically significant predictors of family caregivers' level of being upset. In the context of bathing, family caregiver gender ($\beta = -0.40$) was negatively associated with caregiver level of being upset but frequency of bathing behaviors ($\beta = 0.67$) was a stronger positive association with caregiver upset. Frequency of dressing behaviors ($\beta = -0.55$) had a strong negative association with caregiver level of being upset however; caregiver gender ($\beta = 0.36$) had a positive association with caregiver upset. Lastly, a stronger positive relationship was found between family caregiver gender ($\beta = 1.0$) and family caregiver level upset with eating behaviors than the association between frequency of eating behaviors ($\beta = 0.42$) and family caregiver level of being upset. Overall statistical analysis revealed, a non-significant regression equation for the dependent variable of caregiver level of being upset and the independent variable of frequency of bathing behaviors. Controlling for caregiver gender also resulted in a non-significant f (2, 0.1.40, p = .492) equation with an R^2 of 0.25 and adjusted R^2 of −0.26. The model was not significant although the analysis accounted for 26% of the variance. In the second model with the dependent variable of caregiver upset with the behavior of dressing behaviors and the independent variable of frequency of dressing behaviors controlling for caregiver gender was also non-significant f (2, 0.509, p = .682) with R^2 −0.32 and adjusted R^2 of −0.36 despite the fact that the analysis accounted for 36% of the variance. In the last model with the dependent variable of family caregivers' upset with eating behaviors and the independent

Table 4
Multiple Regression predicting family caregiver level of upset.

Predictor	Family caregiver level of being upset with bathing	
	Beta	*p*
Family caregiver gender	−0.40	.84
Frequency of bathing behaviors	0.67	.40
R^2	0.25	
Adjusted R^2	−0.26	
Overall significance	0.65	

Predictor	Family caregiver level of being upset with dressing	
	Beta	*p*
Family caregiver gender	0.36	.79
Frequency of dressing behaviors	−0.55	.48
R^2	0.32	
Adjusted R^2	−0.36	
Overall significance	0.68	

Predictor	Family caregiver level of being upset with eating	
	Beta	*p*
Family caregiver gender	1.0	.53
Frequency of eating behaviors	0.42	1.0
R^2	0.06	
Adjusted R^2	−0.18	
Overall significance	0.79	

variable of frequency of eating behaviors caregiver gender (f (2, 0.364) = 0.242, p = .760) was controlled resulting in an R^2 of 0.06 and adjusted R^2 of −0.18. The model was not significant and the analysis accounted for only 18% of the variance. See Table 4.

Discussion

When informal caregivers provide assistance with ADLs such as bathing, dressing, and eating, problematic behaviors signaling resistance are more likely to be present.[14] The current study identified that informal caregivers did experience resistive behaviors during ADLs. However, informal caregivers reported that their care recipient might not have displayed all behaviors in all ADL contexts (bathing, dressing, and eating). For example, 35% of informal caregivers reported experiencing resistive behaviors during bathing and/or dressing and a significant 65% of informal caregivers reported experiencing resistive behaviors during eating. It appears that when caregivers provide assistance with eating more behaviors result than when assisting care recipients during bathing or dressing. One explanation for this occurrence maybe that the context of assisting people with dementia when eating may be perceived as more of a threat by the care recipient[16] and result in more resistive behaviors than in the contexts of bathing and dressing.

In addition to reporting of behaviors within certain contexts (bathing, dressing, and eating), informal caregivers were asked to rate the frequency in which they experienced these behaviors as well as caregiver level of being upset when the behaviors occurred. Surprisingly, informal caregivers reported the frequency of behaviors occurred no more than two to six times per week however their reported level of being upset with the behaviors were reported as somewhat to very upset. It appears that behaviors themselves displayed by care recipients are upsetting for caregivers and may not be proportionately related to the frequency of which theses behaviors occur. In fact, 82–100% of informal caregivers perceive the behaviors (during bathing, dressing and eating) to be somewhat upsetting to very upsetting when they occur infrequently.

Further, analysis did show moderate correlations (R value) with caregivers' level of being upset with behaviors (occurring during ADLs such as bathing, dressing, and eating), and explained moderate variance in caregivers' level of upset (R^2 value) while controlling for caregiver gender. Adjusted R^2 values were used for more conservative estimates as too few subjects multiplied by the number of variables had the potential to over inflate true estimates of variance in family caregivers' level of upset. The models were not statistically significant and were attributed again to a small sample size. Future studies on this phenomenon should target larger sample sizes to determine with confidence: whether caregivers' level of upset increases during the ADL context of bathing, as behaviors increased; if a strong negative relationship existed between frequency of dressing behaviors and caregiver perceived level of being upset with the behaviors suggesting that people with dementia who display infrequent behaviors during dressing cause caregivers increased levels of upset; and test family caregiver gender as a predictor of family caregiver upset with behaviors occurring during assisted ADLs.

One thing is certain, informal caregivers' perceptions of distress when the behaviors occurs in context signals that something other than the frequency of the behaviors in context may be contributing to the level of being upset. Further rigorous research is needed to explore more deeply into informal caregivers' experiences with behaviors during caregiver-assisted activities of daily living and to understand the phenomenon. Spigelmyer et al.[17] have studied the lived experience of informal caregivers surrounding resistiveness to care in the context of assisting people with dementia during ADLs and uncovered the meaning assigned to the experience by informal caregivers. Using this study's reported findings along with those of Spigelmyer et al.[17] future research should focus on targeted interventions to help informal caregivers manage their level of upset when the behaviors occur during activities of daily living.

Additionally, this study's gender difference findings suggest that targeted interventions should consider gender differences of caregivers specifically within the context of caregiver assisted ADLs such as bathing, dressing, and eating. Male caregivers in this study were found to report on average providing more assistance with bathing and dressing than female caregivers and male caregivers may require more supportive interventions with these specific ADL tasks. In a scoping review conducted by Bartlett et al.[18] support was found for further research to include gender differences, as the state of current research shows gender is addressed in research however assumptions with female caregiver experiences being reported more prominently than male experiences. The need for gender sensitivity continues and should be used in future studies particularly when studying caregivers' levels of being upset with behaviors such as those occurring during assisted ADLs. Acknowledgement and incorporation of gender differences in caregiving management and coping interventions is paramount and will enable management strategies and interventions in the context of assisted ADLs to be specifically person centered in helping caregivers manage their level of upset during assisted ADLs when resistive behaviors are most likely to occur.

Lastly, this study was conducted to test the feasibility of recruiting informal caregivers from Alzheimer's support group meetings. Although informal caregivers predominantly attend support group meetings, researchers must consider that Alzheimer's support groups typically meet only once a month and that the same people typically attend each of the monthly meetings thus limiting the potential for new participant enrollment each month. In addition, researchers need to consider seasonal aspects of caregiver attendance. Typically in the northeast, during winter months support group meetings are cancelled for holidays and bad weather, which can lengthen the time of recruitment efforts. These were some of the difficulties the researchers encountered in this study. Despite these identified

challenges, support group leaders contacted for this study were overall very welcoming of the researcher and the idea of the research project. Participants also welcomed the researcher. This may have been attributed to the fact that the researcher was also identified as a nurse (a very trusting profession). Knowing these issues, Alzheimer's support groups can be considered as potential recruitment sites for informal caregivers of people with dementia.

Limitations

A limitation of the cross-sectional design is that direct causation cannot be assumed and other alternative explanations may exist for the research findings. Next, this study utilized self-report for data collection. Five of the 17 participants (29%) did not report any behaviors during their caregiving contexts of eating, bathing, and dressing despite indicating to the first author that they had experienced the behaviors during caregiving as part of the inclusion criteria for participation in the study. This led to missing data. A possible explanation is that caregivers had experienced the behaviors but not during the one point in time ("the past week") as indicated on the modified Weekly Behavior Record Scale data collection form. Future studies should use a larger sample size to be more confident in the findings. Another factor that may limit confidence in the findings may have been the reactive effects or Hawthorne effect, in which informal caregivers wanted to present their caregiving situation in the most socially desirable and not report negative aspects to the researcher. A plausible explanation for the lack of reporting restive behaviors may have also been due to the length of time in the caregiving role. Gaugler et al.[11] identified an association between longer periods of caregiving and decreased perceptions of distress with behaviors displayed by care recipients diagnosed with dementia. Although the average length of time caregiving was four years, five caregivers reported longer lengths of time as caregiver. Lastly, it is possible that informal caregivers over or under self-reported both the frequency of the behaviors displayed and their own level of being upset with the behaviors.

In the future, the researchers recommend that research surrounding resistive behaviors and caregivers' perceptions of those behaviors use more objective measures rather than self-reported measures to enable more confidence in the research findings. The authors also acknowledge that to prevent missing data when using questionnaires or surveys as data collection tools, researchers should establish a means to contact participants for clarifications should questions arise during data analysis even with pilot studies. Using a larger sample size and these recommendations will enhance the overall quality of research surrounding the concept of resistive behaviors as experienced by informal caregivers.

Relevance for clinical practice

The findings from this study are relevant for nurses in clinical practice. By increasing nurses' awareness of the phenomenon of resistive behaviors, nurses can be the point person to identify informal caregivers who are experiencing distress related to resistive behaviors. Nurses understanding this phenomenon can also be instrumental in helping informal caregivers obtain the appropriate support they need to manage these upsetting caregiving situations. Nurses sensitive to this study's findings can also be cognizant of gender differences in informal caregivers' perceptions of assistance provided for bathing, dressing and eating and not present materials or support that is gender neutral. Lastly, gender differences may correlate specifically with informal caregivers' level of being upset with the behaviors during assisted ADLs and may precipitate informal caregivers thoughts of placement for their care recipients. In turn, nurses can be active in helping both care recipients with dementia and informal caregivers during this often-difficult transition period.

Conflict of interest

The authors declare that there are no conflict of interest.

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Supplementary materials

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