Factors associated with care-resistant behavior in the National Alzheimer's Coordinating Center's Uniform Dataset

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STRUCTURED ABSTRACT

INTRODUCTION: Little is known about the factors associated with care-resistant behavior in community-dwelling persons living with dementia.

METHODS: Regression modeling of 41,143 responses to a standardized questionnaire from the National Alzheimer's Coordinating Center's Uniform Dataset.

RESULTS In the fully-adjusted mixed-effects regression model, collinearity was low, with no VIF above 1.15. Moderate (aOR = 1.59; 95%CI: 1.50,1.69) and severe (aOR=1.95; 95%CI: 1.82,2.09) dementia severity; and Black/African American (aOR = 1.64; 95%CI: 1.47,1.82), Hispanic ethnicity (aOR 1.13; 95%CI: 1.00, 1.28), frontotemporal (aOR 1.29; 95%CI: 1.12,1.49) and Lewy Body dementia (aOR 1.15; 95%CI: 1.02,1.29) diagnosis type were associated with a higher odds of care-resistant behavior. Female sex (aOR 0.85; 95%CI: 0.80,0.91) and higher education (aOR 0.9, 95%CI: 0.84,0.97) were associated with a lower odds of care-resistant behavior

DISCUSSION: Interventions to manage care-resistant behaviors should consider sociocultural factors as well as type of dementia diagnosis to limit caregiver strain and burden.

BACKGROUND

Care-resistant behavior in persons living with dementia (PLWD) can be defined as the "repertoire of behaviors in which persons with dementia withstand or oppose the efforts of a caregiver."[1] Care-resistant behavior can manifest as physical or verbal behaviors, including aggression and striking the caregiver. Care-resistant behavior includes passive resistance like moving away from the caregiver or becoming unresponsive.[2] More than 67% of caregivers report managing at least one care-resistant behavior, with higher likelihoods of managing care-resistant behavior with severe disease.[2,3]

Managing care-resistant behaviors is associated with negative outcomes for the family caregiver.[4] In addition to physical harm, care-resistant behaviors are associated with increases in caregiver distress, overload and depression[2,5,6] which can lead to hospitalization, and/or institutionalization of PLWD.[4,7]

Management of care-resistant behavior includes strategies like covertly administering medications, including those to treat resistant behavior as well as those to manage symptoms of dementia, or employing interventions to reduce care-resistant behavior.[2,8] While interventions have been shown to positively impact the number of care-resistant behaviors, a systematic review of care-resistant behavior interventions found that 29 out of 30 included studies took place in nursing homes.[2] More work is needed to understand personal factors may affect care-resistant behavior in community-dwelling persons living with dementia.

Personal factors like dementia severity and the demographics of the PLWD are important factors that can affect care-resistant behavior, as highlighted in the Conceptual Framework for Rejection of Care Behaviors.[5] In the early stages of dementia, care-resistant behavior is often due to the PLWD denying the need for assistance, while in later stages may be caused by paranoia, pain, delirium or delusions.[9] However, the strength and direction of the personal factors that may be associated with care-resistant behavior, particularly in community-dwelling persons living with different types of dementia, is unknown.

Understanding the factors associated with care-resistant behavior can help to inform future research in community-dwelling persons living with dementia. The objective of our analysis was to use a large, publicly available dataset of community-dwelling persons living with dementia who receive care at a US-based Alzheimer's Disease Research Center to determine what personal factors are associated with care-resistant behavior. We hypothesized that dementia severity, dementia diagnosis type, and biological sex would be associated with a greater likelihood of care-resistant behavior.

METHODS

Data Source

Data for this project came from the National Alzheimer's Coordinating Center (NACC) Uniform Data Set (UDS).[10] The NACC UDS contains longitudinal data of participants collected since 2005 during standardized annual evaluations at the 34 National Institute on Aging-funded Alzheimer's Disease Research Centers (ADRCs) across the country. The NACC UDS is a publicly-accessible database including standardized cognitive, behavioral, and functional data on persons with dementia. We used data collected between 2005 and 2022. Data is collected at approximately annual follow-ups by trained clinicians and clinic personell through standardized evaluations of participants and co-participants (typically family caregivers) at ADRC visits. Data are recorded directly into NACC UDS forms and uploaded to the overall dataset. While participants are followed for multiple years, new participants are enrolled yearly and others are forced to drop out due to health concerns that prevent them from attending visits or participant death.

Inclusion Criteria

For inclusion in the analysis, participants had to be diagnosed with dementia according to the Clinical Dementia Rating Global Scale (score >=1 on the CDRGS),[11] where scores on cognitive, behavioral, and functional aspects of participant functioning were evaluated by clinicians. Those with no or questionable dementia were excluded from analysis.

Measures

Dementia severity was determined using the Clinical Dementia Rating Global scale.[11] Participants received a score of 0 (no dementia); 0.5 (questionable dementia); 1 (mild dementia); 2 (moderate dementia); or 3 (severe dementia). Only participants with dementia were included in our analysis.

Care-resistant behavior was evaluated using dichotomous question 3 of the Neuropsychiatric Inventory, which is asked by the clinician to the co-participant or family caregiver:[12] "Is the patient resistive to help from others at times, or hard to handle?". While the question is labeled in the "Agitation/Aggression" domain, the question clearly evaluates care-resistant behavior.[13]

Demographic characteristics included sex, race/ethnicity, years of education, and clinician-diagnosed type of dementia. Demographic characteristics were selected *a priori* by the study team based on their clinical expertise and knowledge of the factors as important factors influencing care-resistant behavior in prior literature.[6] Education was dichotomized based on completion of a college degree.

Analytic Strategy

We conducted a mixed-effects exploratory logistic regression analysis on our outcome measure and variables of interest, including a random effect to account for observations by the same participant on multiple years. A pre-defined alpha-level of 0.05 was used to determine statistical significance. We tested for collinearity using the Variance Inflation Factor (VIF) and defined problematic collinearity as a VIF of greater than 10.[14] We did not impute or otherwise include caregivers who provided data with missing responses for the measures included in our model. All analyses were conducted in R Version 3.1 (Boston, MA). This analysis adhered to the Reporting

of Studies Conducted Using Observational Routinely Collected Data (RECORD) reporting guidelines (Supplemental File A).[15]

RESULTS

Participant Characteristics

We analyzed 35,227 responses of participants with Alzheimer's, frontotemporal dementia, and Lewy Body Dementia. Participants were primarily female (n=21121, 51.3%), White (n=35027, 85.6%), and non-Hispanic (n=37401, 91.2%), with a mean age of 75.5. They were primarily diagnosed with Alzheimer's disease (n=31519, 88.3%) and most were considered mild severity (n=21548, 52.4%). More than 57% (n=20,222) of co-participants attested to the person living with dementia displaying care-resistant behavior according to question 3 of the Neuropsychiatric Inventory. See Table 1 for more information on participant demographics.

Statistical Results

In univariate statistical modeling, dementia severity, biological sex, race, education, Hispanic or Latinx ethnicity, age, and type of dementia diagnosis were all associated with care-resistant behavior. See Table 1 for more information.

In the fully-adjusted mixed-effects regression model, collinearity was low, with no VIF above 1.15. Moderate (adjusted odds ratio [aOR] = 1.59; 95% confidence interval [CI]: 1.50, 1.69; p=<0.001) and severe (aOR=1.95; 95% CI: 1.82, 2.09; p=<0.001) dementia severity; and Black/African American (aOR = 1.64; 95% CI: 1.47, 1.82; p=<0.001), Hispanic ethnicity (aOR 1.13; 95%CI: 1.00, 1.28; p=0.043), frontotemporal (aOR 1.29; 95% CI: 1.12, 1.49; p=<0.001) and Lewy Body dementia (aOR 1.15; 95% CI: 1.02, 1.29; p=0.021) diagnosis type were associated with a higher

odds of care-resistant behavior. Female sex (aOR 0.85; 95% CI: 0.80, 0.91; p=<0.001) and higher education (aOR 0.9, 95% CI: 0.84, 0.97; p=<0.001) were associated with a lower odds of care-resistant behavior (Table 2).

DISCUSSION

In analyzing data from this large national survey, we found that the most significant factors associated with care-resistant behavior were disease severity, Black/African American race, and type of dementia.

The presence of care-resistant behavior was more likely as dementia severity increases. This finding echoes the findings of other researchers.[3,16] Ishii et al. found that, compared to mild/moderate dementia, severe dementia was associated with a 1.92 greater odds of the likelihood of care-resistant behaviors in non-community dwelling PLWD, though their meta-analysis did not adjust for additional demographic factors[3]. Our results indicate that these associations are robust when adjusting for demographics including age, biological sex, race/ethnicity, and type of dementia diagnosis. Indeed, we found stepwise increases in the likelihood of exhibiting care-resistant behavior between mild, moderate, and severe dementia, indicating that those with severe dementia could be a group that may benefit most from targeted interventions.

In line with prior research, we found that Black/African American and Hispanic/Latinx PLWD were more likely to exhibit care-resistant behavior, but we were unable to categorize which specific care-resistant behaviors were being exhibited.[3] In an adjusted model examining verbal aggression by different PLWD races/ethnicities, Hansen et al. found that Black/African American PLWD were more likely to demonstrate verbal aggression in response to caregiver behavior than White

PLWD.[17] Future work should categorize the various care-resistant behavioral responses in order to tailor interventions to specific care-resistant behaviors. Targeted support for carers of Black/African American and Hispanic PLWD may be beneficial.

Compared to caregivers of patients with Alzheimer's disease, caregivers of frontotemporal dementia or Lewy Body Dementia have shown higher levels of caregiver burden.[18] Our finding of a higher odds of care-resistant behavior in patients with frontotemporal dementia and Lewy Body Dementia compared to patients with Alzheimer's disease is worth exploring. People living with frontotemporal dementia, a cortical dementia, tend to have more neuropsychiatric symptoms than people with subcortical dementias such as Lewy Body Dementia.[19]12/19/2024 5:06:00 PM People with Lewy Body dementia are more likely to experience hallucinations compared with other dementias;[20]12/19/2024 5:06:00 PM perhaps the presence of hallucinations fuel care-resistant behavior. People living with frontotemporal dementia, either behavioral or semantic, tend to be younger compared to people living with Alzheimer's dementia, which increases the social and economic burden of caregivers who are unable to obtain resources.[21] While our cross-sectional analysis cannot comment on causality, care-resistant behavior could be a modifiable factor affecting caregiver burden in future research. Furthermore, there is a need for additional research testing if specific strategies are more effective in reducing care-resistant behavior in specific types of dementia.

Strengths and Limitations

This was an analysis of a large sample from a multi-year, multi-site database. The measures included are demographic variables or patient, caregiver, or clinician-reported validated scales,

and therefore likely to be reliable. However, while our analysis identifies factors associated with the likelihood of care refusal behaviors, we were unable to examine which behaviors, like physical aggression or verbal refusals, may be present. Similarly, we were unable to identify which activities, like brushing teeth or managing medications, were being refused. An important limitation of this dataset is the sampling population. While it is a standard evaluation given across time at 34 Alzheimer's Disease Research Centers across the US, this is considered a convenience sample and is not representative or generalizable. For instance, prior work from ADRCs have shown that Black participants were diagnosed at lower rates than White participants,[22] despite multiple studies reporting that non-Hispanic Black individuals are diagnosed with dementia at higher rates than non-Hispanic White individuals.[23–25] Future work could consider providing the standard ADRC evaluation at non-ADRC clinics to better understand how these results are applicable to non-ADRC populations.

Conclusions/Implications

While some of our findings, such as care-resistant behavior displayed by PLWD intensifying as dementia severity and dependency increase, support the findings of other studies. Our finding that different types of dementia, such as frontotemporal dementia and Lewy Body Dementia, are associated with more care refusals than Alzheimer's disease, suggests that interventions for refusals may need to be tailored according to the type of dementia—an area that would benefit from more exploration.

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Consent Statement
Consent was not necessary for our analysis.