Specific agitation behaviours in dementia differentially contribute to aspects of caregiver burden

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Abstract

Background: Agitation is a common symptom in dementia and linked to caregiver burden, but both agitation and burden are multidimensional constructs. The current study sought to determine whether specific presentations of agitation differentially relate to aspects of caregiver burden.

Methods: Medical record data from an outpatient memory clinic were extracted for 609 persons with dementia, including caregiver-reported burden and care recipient agitation.

Results: Exploratory factor analysis yielded three domains of agitation on the Cohen Mansfield Agitation Inventory ('Physically Aggressive', 'Physically Non-Aggressive', 'Verbally Agitated') and four domains of burden on the Zarit Burden Interview ('Impact on Life', 'Guilt/Uncertainty', 'Embarrassment/Frustration', 'Overwhelm'). Regression analyses demonstrated all domains of agitation positively predicted overall burden. Regarding specific aspects of burden, Physically Aggressive behaviours predicted Embarrassment/Frustration. Physically Non-Aggressive behaviours predicted Impact on Life and Guilt/Uncertainty. Verbally Agitated behaviours predicted all burden dimensions.

Conclusions: Results suggest specific aspects of agitation may differentially contribute to facets of caregiver burden.

INTRODUCTION

Agitation is a prevalent neuropsychiatric symptom within the dementia spectrum, experienced by 70% of individuals with cognitive decline.1 A robust literature demonstrates a strong association between agitation and burden in caregivers of individuals with dementia, as these symptoms are difficult to manage and predict, and can be disruptive or embarrassing.2–5 Given the high prevalence of agitation in dementia and its strong correlations with burden in caregivers, understanding how these symptoms in the person with dementia might influence burden in the caregiver is imperative. However, both agitation and caregiver burden are complex constructs.

Agitation in dementia involves a range of behaviours including increased motor activity (e.g., restlessness, pacing), aggressive behaviours, and emotional distress.1 Some work has broadly categorized agitation behaviours into physically aggressive behaviour (e.g., hitting, throwing things, grabbing), physically non-aggressive behaviour (e.g., pacing/aimless wandering, repetitive mannerisms, restlessness), and verbally agitated behaviour (e.g., negativism, complaining, unwarranted requests for attention or help).6 However, efforts to understand such behaviours have not led to fully consistent classification,7 which complicates understanding of how these symptoms might impact burden.

Caregiver burden is also a multi-faceted construct, but commonly incorporates dimensions of emotional, social/relationship, and physical health strain.3 Prior research demonstrates that the multidimensional construct of caregiver burden generally shows at least two factors (personal versus role strain),8,9 but commonly three or more, in which affective aspects...
of burden (e.g., guilt, embarrassment, frustration, uncertainty) do not consistently align with one another).\textsuperscript{10–14}

Exploration of relationships between agitation and aspects of burden would facilitate greater understanding of whether specific presentations or types of agitation elicit distinctive patterns of caregiver burden. For example, it is possible that physically non-aggressive agitation behaviours (e.g., inappropriate dress, disrobing) lead to embarrassment, whereas physically aggressive behaviours (e.g., hitting, throwing things) or verbal agitation (e.g., negativism; constant, unwarranted requests for attention or help; repetitive questions) are more likely to elicit a response of frustration in the caregiver. Cognizance of common patterns in the relationships among agitation and aspects of burden could help clinicians better support a caregiver facing these challenges.

To our knowledge, little work has examined associations among factors of agitation in the individual with dementia and burden in the caregiver. The current study sought to investigate the factor structure of two commonly used measures of these domains (the Cohen Mansfield Agitation Index (CMAI),\textsuperscript{15} and the Zarit Burden Inventory (ZBI)\textsuperscript{16}), exploring how specific factors of agitation contribute to caregiver burden overall, and whether these domains of agitated behaviour differentially relate to specific aspects of caregiver burden.

**METHODS**

**Participants**

Participants were drawn from a registry of 1013 care recipient-caregiver dyads, continuously enrolled at an outpatient memory clinic in Northeast Ohio. Inclusion criteria were as follows: (i) clinically supported dementia spectrum diagnosis given by a geriatrician after comprehensive evaluation; and (ii) caregiver completion of measures gathered for clinical use. Exclusion criteria were missing data on measures of primary and control variables. Care recipients living in structured care facilities were retained, as caregiver burden often persists after a care recipient is admitted to a care facility.\textsuperscript{17} The final analysed sample included 609 care recipient-caregiver dyads.

**Measures**

**Primary variables**

Agitation behaviours. The CMAI assessed caregiver ratings of agitation in the care recipient.\textsuperscript{15} The CMAI is a widely used, well-validated measure of agitation in persons with dementia,\textsuperscript{18} known for its ability to capture granularity of symptoms related to agitation.\textsuperscript{19} Caregivers rated the frequency of 29 behaviours (e.g., restlessness, hitting, cursing, pacing) on a 7-point Likert scale (1 = Never, to 7 = Several times an hour). Item scores were summed, and higher scores indicate greater agitation-related symptoms in the care recipient.

Caregiver burden. The ZBI\textsuperscript{16} is a 22-item measure of caregiver burden in which the caregiver reports the frequency of items on a scale of 0 (Never) to 4 (Nearly always). Item scores were summed, and higher scores indicate greater burden. The ZBI is well-validated, with strong psychometric properties.\textsuperscript{8,16}

**Control variables**

Global cognitive screening. The Montreal Cognitive Assessment (MoCA)\textsuperscript{20} or the Mini-Mental State Examination (MMSE)\textsuperscript{21} were used as measures of global cognitive functioning. The MoCA and MMSE are brief cognitive screening tools involving tests of orientation, executive functioning, visuospatial function, calculation, language recall, abstraction, and attention that have shown sensitivity and specificity in older adults in detecting cognitive impairment.\textsuperscript{20,22–24} At their initial appointment, care recipients were administered either the MoCA or MMSE at the time of their initial outpatient visit. Scores were standardized into T-scores based on normative data,\textsuperscript{25,26} and T-scores were then combined into a single cognitive screening variable.

Activities of daily living. Prior work suggests activities of daily living are a useful proxy for dementia severity.\textsuperscript{27} Caregivers reported the amount of support the care recipient received in completing basic activities of daily living including bathing, dressing, toileting, feeding, and transfers, along with instrumental activities including telephone use, transportation, shopping, meal preparation, housework, medication use, and handling finances. Caregiver responses were rated on a scale of level of functioning (1 = independent, 2 = assisted, 3 = dependent) by a geriatric social worker at the time of the initial outpatient visit.
Scores were then summed, with higher total scores indicating greater impairment.

**Demographic information.** Additional demographic information of the caregiver and care recipient was extracted from the clinic registry, including caregiver age, sex, years of education, and relationship to the care recipient, and care recipient age, sex, race, and years of education.

**Procedure**

Procedures followed the reporting of studies conducted using observational routinely collected health data (RECORD) guidelines and were approved by the Kent State University and Summa Health System Institutional Review Boards. The study included outpatient care recipients who registered for clinic care consecutively between April 2017 and April 2019. Data from electronic medical charts included in a clinical registry were extracted for caregiver-care recipient dyads.

**Statistical power**

A subject-to-item ratio of 10:1 or more is recommended for exploratory factor analysis (EFA), suggesting that the size of the current sample was sufficient. An a priori power analysis assessed the minimum sample size needed for multiple regression analyses investigating the impact of CMAI factors on ZBI factor scores. Based on small effects found in prior work examining the associations between agitation behaviours and caregiver burden ($r = 0.25$), Power analyses with $\alpha = 0.05$ and power ($1 - \beta$) = 0.08 suggested a minimum sample size of 123.

**Statistical analyses**

The factor structure of the CMAI in the current outpatient sample was examined with an EFA with principal axis factoring and direct oblimin rotation. CMAI items endorsed by fewer than 5% of caregivers were excluded from analyses based on prior work excluding rare behaviours at this cutoff. These items included intentionally falling, hurting the self or others, spitting, scratching, pushing, biting, kicking, making physical and verbal sexual advances, and eating/drinking inappropriate substances. Aside from spitting, these items were excluded in prior work analysing the factor structure of the CMAI in individuals living in the community due to low rates of occurrence. Total scores for each factor were obtained from sums of item scores from each factor. The factor structure of the ZBI was examined with an EFA with principal axis factoring and direct oblimin rotation. As item 22 of the ZBI measures overall subjective feeling of burden in the caregiver, it was removed from the analysis. Total scores for each factor were obtained from sums of item scores from each factor.

Total CMAI factor scores were then entered into a hierarchical multiple regression analysis to explore their unique contributions to total ZBI scores. In the first step of the regression, caregiver age and relation to the care recipient, caregiver years of education, care recipient years of education, care recipient sex, and care recipient race were entered as control variables, based on prior work indicating relationships between these variables and caregiver burden and significant correlations with primary variables. Care recipient age and caregiver sex were considered as control variables but not included as they did not show significant relationships with primary variables in this sample. Additionally, scores on global cognitive functioning measures administered at the care recipient’s visits to the memory clinic were entered in the first step as a control for dementia severity. Care recipients’ ability to complete basic activities of daily living, and instrumental activities of daily living, were also included in the first step as a control for dementia severity. Total scores for each CMAI factor were included in the second step of the regression. Then, total CMAI factor scores were entered into separate hierarchical multiple regression analyses to explore their unique contributions to specific ZBI factors. Again, control variables described above were included in the first step of the regression and total scores for each CMAI factor were included in the second step. Each ZBI factor was included as the dependent variable in a separate regression with the same first and second steps. SPSS Version 28 was used for all analyses.

**RESULTS**

**Participant demographics**

Caregivers were on average 63 years of age. Most were female (69.5%) adult children (56.1%) or spouses (30.8%) of the care recipient. Care recipients were also more likely to be female (65.7%) and
on average approximately 82 years of age. See Table 1 for sample characteristics and descriptive statistics for primary variables.

Factor analysis of the Cohen-Mansfield Agitation Inventory
Exploratory factor analysis results initially supported a seven-factor structure that explained 62% of the variance with eigenvalues >1. However, based on scree plot results, requiring minimum factor loadings of 0.4, and requiring that the number of items in each factor be greater than or equal to three as suggested by prior work,31,36,37 the number of extracted factors was limited to three. Results supported three robust factors accounting for 52.45% of the total variance and aligned with prior work, finding factors of ‘Physically Aggressive’, ‘Physically Non-Aggressive’, and ‘Verbally Agitated’ behaviours. In the current study CMAI items loading on the Physically Aggressive behaviours factor were hitting, throwing things, destroying property, and grabbing people. Items loading on the Physically Non-Aggressive behaviours factor were pacing/aimless wandering, trying to get to a different place, hiding, hoarding, performing repetitive mannerisms, general restlessness, inappropriate dress or disrobing, and handling things inappropriately. Items loading on the Verbally Agitated behaviours factor were negativity; complaining; constant, unwarranted requests for attention or help; cursing or verbal aggression; repetitive sentences or questions; and screaming. The CMAI item ‘making strange noises’ did not load highly on any of the three factors and was not included in further analyses. Table 2 displays full item loading on factors. See Table 3 for correlations among factors.

Factor analysis of the Zarit Burden Interview
Exploratory factor analysis results supported a four-factor structure that explained 63% of the variance with eigenvalues >1. Factor 1 (‘Impact on Life’) included items related to feelings of a loss of control over life, stress, lack of money, personal health decline, not having time to spend on themselves, lack of privacy, feeling unable to care for the care recipient much longer, and wishing that they could leave the care of their relative to someone else. Factor 2 (‘Guilt/Uncertainty’), included items related to feeling that they could and should be doing more for their relative, feeling uncertain about what to do, and feeling afraid of what the future will hold. Factor 3 (‘Embarrassment/Frustration’) involved items related to embarrassment and anger, feeling uncomfortable having friends over, and negative effects on relationships with other family members or friends. Factor 4 (‘Overwhelm’) involved items related to feeling like their relative is dependent on them, feeling that their relative expects care as if they were the only one their relative could depend on, and feeling that their relative asks for more help than they need. The item, ‘do you feel strained when you are around your relative’ loaded equally on both Factor 1 and Factor 3 and was not included in further analyses. Table 2 displays full item loading on factors. See Table 3 for correlations among factors.

Table 1 Demographics and descriptive statistics

| Caregiver demographics | N = 609 |
|------------------------|--------|
| Age (M/SD, range)      | 62.9/13.0, 23–90 |
| Sex (%)                |        |
| Male                   | 30.5%  |
| Female                 | 69.5%  |
| Education ≥ 12 years (%)| 98.6% |
| Caregiver relationship (%)|    |
| Spouse                 | 30.8%  |
| Adult child            | 56.1%  |
| Other                  | 13.1%  |
| Care recipient demographics |        |
| Age (M/SD, range)      | 82.1/6.2, 67–90 |
| Sex (%)                |        |
| Male                   | 34.3%  |
| Female                 | 65.7%  |
| Education ≥ 12 years (%)| 84.0% |
| Race or ethnicity (%)  |        |
| White/Caucasian        | 91.0%  |
| Black/African American  | 7.8%  |
| Asian                  | 0.5%   |
| Hispanic/Latinx        | 0.3%   |
| Other                  | 0.4%   |
| Diagnosis              |        |
| Alzheimer’s disease    | 34.1   |
| Vascular dementia      | 6.4    |
| Dementia with Lewy bodies| 1.3  |
| Frontotemporal dementia| 0.5   |
| Mild cognitive impairment| 15.0 |
| Mixed/other            | 42.7   |
| Descriptive statistics for primary variables (M/SD, range) |        |
| Zarit Burden Interview (ZBI) | 28.1/16.7, 0–78 |
| Cohen Mansfield Agitation Inventory (CMAI) | 44.1/15.3, 7–126 |
| Montreal Cognitive Assessment (MoCA) | 16.5/5.6, 1–30 |
| Mini-Mental State Examination (MMSE) | 12.0/4.9, 2–26 |
Contribution of Cohen Mansfield Agitation Inventory (CMAI) factors to overall Zarit Burden Interview scores

Accounting for control variables, the addition of the CMAI factors resulted in an $\Delta R^2$ of 0.24, with the total model accounting for 32.1% of the variance in ZBI scores. Verbally Agitated behaviours ($B = 0.92$, $SE = 0.06$, $\beta = 0.41$, $P < 0.001$), Physically Aggressive behaviours ($B = 0.12$, $SE = 0.09$, $\beta = 0.09$, $P = 0.01$), and Physically Non-Aggressive behaviours ($B = 0.21$, $SE = 0.10$, $\beta = 0.10$, $P = 0.04$) were significantly associated with greater ZBI scores. The overall regression equation was significant in the final model ($R^2 = 0.321$, $F(11, 609) = 25.69$, $P < 0.001$). See Table 6 for regression results.

**Table 2** Pattern matrix from the Cohen Mansfield Agitation Inventory (CMAI) factor analysis with oblimin rotation

| CMAI Item                                      | Physically Non-Aggressive behaviours | Physically Aggressive behaviours | Verbally Agitated behaviours |
|-----------------------------------------------|--------------------------------------|----------------------------------|------------------------------|
| Pacing, aimless wandering                     | 0.790*                               | −0.063                           | −0.019                       |
| Trying to get to a different place            | 0.747*                               | 0.039                            | 0.123                        |
| Hiding things                                 | 0.707*                               | 0.102                            | −0.031                       |
| Performing repetitious mannerisms             | 0.632*                               | 0.158                            | −0.272                       |
| General restlessness                          | 0.614*                               | −0.194                           | −0.379                       |
| Inappropriate dress or disrobing              | 0.612*                               | 0.111                            | 0.187                        |
| Hoarding things                               | 0.594*                               | 0.136                            | −0.084                       |
| Handling things inappropriately               | 0.458*                               | 0.073                            | −0.200                       |
| Throwing things                               | −0.089                               | 0.793*                           | −0.145                       |
| Hitting                                       | −0.009                               | 0.730*                           | 0.017                        |
| Tearing things or destroying property         | 0.189                                | 0.678*                           | 0.055                        |
| Grabbing onto people                          | 0.089                                | 0.461*                           | −0.095                       |
| Negativism                                    | −0.043                               | 0.009                            | −0.909*                      |
| Complaining                                   | −0.011                               | 0.021                            | −0.871*                      |
| Constant unwarranted request for help         | 0.024                                | 0.176                            | −0.667*                      |
| Cursing or verbal aggression                  | 0.067                                | 0.339                            | −0.530*                      |
| Repetitive sentences or questions             | 0.294                                | −0.165                           | −0.505*                      |
| Screaming                                     | 0.058                                | 0.300                            | −0.491*                      |
| Percent variance explained                   | 35.12                                | 9.59                             | 7.75                         |

Note: * is used to identify the strongest factor loading for each item.

**Table 3** Cohen Mansfield Agitation Inventory factor correlation matrix

| Factor                      | Physically Non-Aggressive | Physically Aggressive |
|-----------------------------|---------------------------|-----------------------|
| Physically Non-aggressive   | –                         | –                     |
| Physically Aggressive       | 0.275                     | –                     |
| Verbally Agitated           | −0.448                    | −0.259                |

**Contribution of Cohen Mansfield Agitation Inventory factors to Zarit Burden Interview Factors**

**ZBI Impact on Life**

Accounting for covariates, the addition of the CMAI factors resulted in an $\Delta R^2$ of 0.18, with the total model accounting for 29.8% of the variance in ZBI Impact on Life scores. Both Verbally Agitated behaviours ($B = 0.35$, $SE = 0.06$, $\beta = 0.32$, $P < 0.001$) and Physically Non-Aggressive behaviours ($B = 0.14$, $SE = 0.05$, $\beta = 0.13$, $P < 0.01$) were significantly associated with greater ZBI Impact on Life scores. Physically Aggressive behaviours were not significantly associated with ZBI Impact on Life scores. The overall regression equation was significant in the final model ($R^2 = 0.298$, $F(11, 609) = 23.04$, $P < 0.001$). See Table 6 for regression results.

**ZBI Guilt/Uncertainty**

Accounting for covariates, the addition of the CMAI factors resulted in an $\Delta R^2$ of 0.09, with the total model accounting for 14.1% of the variance in ZBI Guilt/Uncertainty scores. Both Verbally Agitated behaviours ($B = 0.12$, $SE = 0.03$, $\beta = 0.22$, $P < 0.001$) and Physically Non-aggressive behaviours...
(B = 0.05, SE = 0.02, β = 0.10, P < 0.05) were significantly associated with greater ZBI Guilt/Uncertainty scores. Physically Aggressive behaviours were not significantly associated with ZBI Guilt/Uncertainty scores. The overall regression equation was significant in the final model (R² = 0.141, F(11, 609) = 8.93, P < 0.001). See Table 6 for regression results.

**ZBI Embarrassment/Frustration**

Accounting for covariates, the addition of the CMAI factors resulted in an ΔR² of 0.22, with the total model accounting for 25.4% of the variance in ZBI Embarrassment/Frustration scores. Both Verbally Agitated behaviours (B = 0.17, SE = 0.02, β = 0.38, P < 0.001) and Physically Aggressive behaviours (B = 0.41, SE = 0.10, β = 0.16, P < 0.001) were significantly associated with greater ZBI Embarrassment/Frustration scores. Physically Non-Aggressive behaviours were not significantly associated with ZBI Embarrassment/Frustration scores. The overall regression equation was significant in the final model (R² = 0.254, F(11, 609) = 18.50, P < 0.001). See Table 6 for regression results.

**ZBI Overwhelm**

Accounting for covariates, the addition of the CMAI factors resulted in an ΔR² of 0.15, with the total model accounting for 28.2% of the variance in ZBI Overwhelm scores. Verbally Agitated behaviours were significantly associated with greater ZBI Overwhelm scores (B = 0.075, SE = 0.272, β = 0.38, P < 0.001). Physically Aggressive and Physically Non-Aggressive behaviours were not significantly associated with ZBI Overwhelm scores. The overall regression equation was significant in the final model (R² = 0.282, F(11, 609) = 28.30, P < 0.001). See Table 6 for regression results.

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**Table 4 Pattern matrix from the Zarit Burden Interview (ZBI) factor analysis with oblimin rotation**

| ZBI Item                | Impact on Life | Guilt/Uncertainty | Embarrassment/Frustration | Overwhelm |
|-------------------------|----------------|-------------------|---------------------------|-----------|
| Lost control of life    | 0.797*         | 0.060             | 0.060                     | −0.029    |
| Social life has suffered| 0.787*         | −0.090            | 0.052                     | 0.134     |
| Not enough time for yourself | 0.734*      | 0.005             | −0.163                    | 0.310     |
| Lack of privacy         | 0.720*         | −0.173            | 0.208                     | 0.048     |
| Personal health has suffered | 0.674*     | 0.024             | 0.219                     | 0.043     |
| Leave care to someone else | 0.629*      | 0.190             | 0.034                     | −0.030    |
| Unable to care          | 0.625*         | 0.334             | −0.077                    | −0.071    |
| Stressed caring for loved one | 0.534*      | 0.215             | −0.033                    | 0.292     |
| Not enough money        | 0.387*         | 0.272             | 0.045                     | 0.046     |
| Should be doing more    | −0.075         | 0.897*            | 0.009                     | −0.061    |
| Could do a better job   | −0.047         | 0.837*            | 0.049                     | −0.038    |
| Uncertain about what to do | 0.208       | 0.643*            | 0.032                     | 0.031     |
| Afraid of what the future holds | 0.027    | 0.571*            | 0.067                     | 0.184     |
| Embarrassed over behaviour | −0.094      | 0.073             | 0.783*                    | 0.171     |
| Angry                   | 0.079          | 0.175             | 0.696*                    | 0.066     |
| Uncomfortable having friends over | 0.407    | −0.040            | 0.590*                    | −0.108    |
| Affects other relationships | 0.374        | 0.043             | 0.531*                    | 0.027     |
| Asks for more help than needed | 0.145    | −0.020            | 0.266                     | 0.745*    |
| Expects care            | 0.151          | 0.034             | 0.084                     | 0.720*    |
| Loved one is dependent  | 0.272          | 0.066             | −0.234                    | 0.689*    |
| Percent variance explained | 43.51        | 8.16              | 6.51                      | 5.17      |

Note: * is used to identify the strongest factor loading for each item.

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**Table 5 Zarit Burden Interview factor correlation matrix**

| Factor                | Impact on Life | Guilt/Uncertainty | Embarrassment/Frustration |
|-----------------------|----------------|-------------------|---------------------------|
| Impact on Life        | −              | −                 | −                         |
| Guilt/Uncertainty     | 0.435          | −                 | −                         |
| Embarrassment/Frustration | 0.380      | 0.235             | −                         |
| Overwhelm             | 0.430          | 0.241             | 0.265                     |
Table 6 Regression model of CMAI on ZBI total and ZBI factors

| Predictors                                      | $b$   | SE  | $\beta$ | $P$   | 95% CI          |
|------------------------------------------------|-------|-----|---------|-------|-----------------|
| **Control variables**                          |       |     |         |       |                 |
| Caregiver age                                  | -0.04 | 0.06| -0.03   | 0.49  | -0.15 to 0.07   |
| Caregiver relationship                         | -0.65 | 0.88| -0.03   | 0.47  | -2.50 to 1.25   |
| Caregiver education                            | 0.39  | 0.20| 0.07    | 0.03* | -0.06 to 0.75   |
| Care recipient race                            | 0.77  | 1.09| 0.03    | 0.49  | -1.38 to 2.90   |
| Care recipient sex                             | 1.04  | 1.43| 0.03    | 0.46  | -1.78 to 3.88   |
| Care recipient education                       | 0.33  | 0.24| 0.05    | 0.16  | -0.14 to 0.80   |
| Severity (cognitive screening)                 | 0.02  | 0.03| 0.04    | 0.48  | -0.03 to 0.07   |
| Activities of daily living                     | 0.92  | 0.16| 0.29    | 0.001** | -0.43 to 0.46 |
| **Introducing CMAI factors to ZBI total**      |       |     |         |       |                 |
| Caregiver age                                  | -0.02 | 0.05| -0.01   | 0.73  | -0.11 to 0.08   |
| Caregiver relationship                         | -1.23 | 0.86| -0.06   | 0.15  | -2.98 to 0.42   |
| Caregiver education                            | 0.33  | 0.17| 0.06    | 0.04* | -0.05 to 0.65   |
| Care recipient race                            | 1.21  | 1.11| 0.05    | 0.28  | -0.98 to 3.38   |
| Care recipient sex                             | 0.24  | 1.23| 0.01    | 0.85  | -2.12 to 2.73   |
| Care recipient education                       | 0.35  | 0.22| 0.06    | 0.11  | -0.07 to 0.78   |
| Severity (cognitive screening)                 | 0.02  | 0.02| 0.03    | 0.45  | -0.03 to 0.05   |
| Activities of daily living                     | 0.44  | 0.14| 0.14    | 0.002** | 0.17 to 0.72 |
| Verbally agitated behaviors                    | 0.92  | 0.10| 0.41    | 0.001** | 0.72 to 1.13 |
| Physically aggressive behaviors                 | 1.20  | 0.55| 0.09    | 0.03* | 0.11 to 2.26   |
| Physically non-aggressive behaviors            | 0.21  | 0.10| 0.10    | 0.04* | 0.01 to 0.41   |
| **Introducing CMAI factors to ZBI impact on life** |       |     |         |       |                 |
| Caregiver age                                  | 0.01  | 0.02| 0.01    | 0.82  | -0.04 to 0.05   |
| Caregiver relationship                         | -0.44 | 0.42| -0.05   | 0.28  | -1.27 to 0.48   |
| Caregiver education                            | 0.09  | 0.09| 0.04    | 0.25  | -0.11 to 0.27   |
| Care recipient race                            | 0.94  | 0.55| 0.07    | 0.09  | -0.16 to 2.01   |
| Care recipient sex                             | 0.08  | 0.58| 0.01    | 0.88  | -1.07 to 1.25   |
| Care recipient education                       | 0.08  | 0.11| 0.03    | 0.42  | -0.11 to 0.28   |
| Severity (cognitive screening)                 | 0.003 | 0.01| 0.01    | 0.86  | -0.02 to 0.03   |
| Activities of daily living                     | 0.32  | 0.07| 0.21    | 0.001** | 0.19 to 0.47 |
| Verbally agitated behaviors                    | 0.35  | 0.06| 0.32    | 0.001** | 0.25 to 0.47 |
| Physically aggressive behaviors                 | 0.44  | 0.25| 0.07    | 0.07  | -0.04 to 0.91   |
| Physically non-aggressive behaviors            | 0.14  | 0.05| 0.13    | 0.005** | 0.04 to 0.24 |
| **Introducing CMAI factors to ZBI guilt/uncertainty** |       |     |         |       |                 |
| Caregiver age                                  | -0.04 | 0.01| -0.12   | 0.009** | -0.06 to -0.01 |
| Caregiver relationship                         | -0.07 | 0.22| -0.01   | 0.76  | -0.50 to 0.37   |
| Caregiver education                            | 0.08  | 0.05| 0.07    | 0.06  | -0.02 to 0.18   |
| Care recipient race                            | -0.21 | 0.25| -0.03   | 0.40  | -0.68 to 0.28   |
| Care recipient sex                             | 0.46  | 0.32| 0.06    | 0.16  | -0.14 to 1.13   |
| Care recipient education                       | 0.18  | 0.06| 0.12    | 0.001** | 0.07 to 0.29 |
| Severity (cognitive screening)                 | 0.003 | 0.01| 0.03    | 0.52  | -0.01 to 0.01   |
| Activities of daily living                     | -0.01 | 0.04| -0.02   | 0.72  | -0.09 to 0.06   |
| Verbally agitated behaviors                    | 0.12  | 0.03| 0.22    | 0.001** | 0.06 to 0.17 |
| Physically aggressive behaviors                 | 0.21  | 0.12| 0.07    | 0.09  | -0.04 to 0.46   |
| Physically non-aggressive behaviors            | 0.05  | 0.03| 0.10    | 0.05* | -0.002 to 0.10  |
| **Introducing CMAI factors to ZBI embarrassment/frustration** |       |     |         |       |                 |
| Caregiver age                                  | -0.01 | 0.01| -0.05   | 0.27  | -0.03 to 0.01   |
| Caregiver relationship                         | -0.51 | 0.17| -0.13   | 0.003** | -0.83 to -0.18 |
| Caregiver education                            | 0.05  | 0.05| 0.04    | 0.29  | -0.07 to 0.11   |
| Care recipient race                            | 0.22  | 0.21| 0.04    | 0.29  | -0.19 to 0.64   |
| Care recipient sex                             | -0.59 | 0.27| -0.09   | 0.03  | -1.10 to -0.06  |
| Care recipient education                       | 0.11  | 0.05| 0.04    | 0.03  | 0.02 to 0.21    |
| Severity (cognitive screening)                 | 0.004 | 0.004| 0.04  | 0.37  | -0.01 to 0.01   |
| Activities of daily living                     | -0.02 | 0.03| -0.03   | 0.44  | -0.08 to 0.03   |
| Verbally agitated behaviors                    | 0.17  | 0.02| 0.38    | 0.001** | 0.12 to 0.22 |
| Physically aggressive behaviors                 | 0.41  | 0.14| 0.16    | 0.003** | 0.16 to 0.69 |
| Physically non-aggressive behaviors            | 0.01  | 0.02| 0.03    | 0.61  | -0.03 to 0.06   |
| **Introducing CMAI factors to ZBI overwhelm**   |       |     |         |       |                 |
| Caregiver age                                  | 0.03  | 0.01| 0.14    | 0.001** | 0.02 to 0.05 |

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DISCUSSION

This study explored how various agitation behaviours in a person with dementia contribute to caregiver burden overall and examined whether domains of agitation differentially relate to specific aspects of caregiver burden. Analyses yielded three domains of agitation on the CMAI (Physically Aggressive, Physically Non-Aggressive, Verbally Agitated) and four domains of caregiver burden on the ZBI (Impact on Life, Guilt/Uncertainty, Embarrassment/Frustration, Overwhelm). Results suggest that all domains of agitation were significantly associated with greater overall caregiver burden scores. Examining the relationship between these factors of agitation and specific aspects of caregiver burden, Physically Aggressive behaviours predicted Embarrassment/Frustration, Physically Non-Aggressive behaviours predicted Impact on Life and Guilt/Uncertainty, and Verbally Agitated behaviours predicted all aspects of burden (Impact on Life, Guilt/Uncertainty, Embarrassment/Frustration, Overwhelm).

Findings from the current study’s factor analysis of the ZBI are generally consistent with past studies showing dimensions of direct impact of caregiving on the caregiver’s life, embarrassment/frustration, uncertainty about the future, and guilt.\textsuperscript{10,12,13,38} While the Overwhelm dimension did not align directly with prior work, Anki and colleagues’ factor analysis\textsuperscript{12} yielded a factor including the three items loading on the current study’s Overwhelm factor: ‘Do you feel that your relative asks for more help than he/she needs?’, ‘Do you feel that your relative is dependent on you?’; ‘Do you feel your relative is dependent on you?’ as if you were the only one he/she could depend on?’). Those authors did not include that fourth factor due to concerns that the items overlapped different dimensions of burden. However, in the current work, Overwhelm appeared to be distinct in capturing the strain of perceived dependency of the care recipient, and over-reliance on the caregiver. Overwhelm could present a unique aspect of caregiver burden, and indeed, in the current study, this factor was differentially predicted by type of agitated behaviour in the care recipient, relative to other factors of burden.

Findings of the current study’s factor analysis of the CMAI are consistent with prior work yielding three factors. A study of the CMAI in persons with dementia receiving facility-based or home-based nursing home care found three factors (Physical Aggression, Physically Non-Aggressive behaviour, Verbally Agitated behaviour),\textsuperscript{6} as did an EFA of the CMAI in a sample of individuals living in long-term care facilities.\textsuperscript{39} An EFA of the CMAI in a community-dwelling sample also resulted in three factors aligned with other work.\textsuperscript{37} Although some prior work has suggested four factors (Aggressive Behaviour, Physically Non-Aggressive Behaviour, Verbally Agitated Behaviour, and Hiding/Hoarding behaviour),\textsuperscript{15,36} studies with these findings were largely conducted with individuals living in care facilities rather than community samples or restricted in dementia diagnoses. Restricting diagnoses can be limiting, as neuropsychiatric symptoms including agitation are seen in individuals with mild cognitive impairments and in subtypes of dementia (Alzheimer’s disease, vascular

\(R^2 = 0.282, \ F(11, 609) = 21.39, \ P < 0.001\). See Table 6 for regression results.

### Table 6 Continued

| Predictors                             | \(b\)  | SE   | \(\beta\) | \(P\)   | 95% CI          |
|----------------------------------------|-------|------|-----------|---------|-----------------|
| Caregiver relationship                 | -0.18 | 0.14 | -0.05     | 0.20    | -0.45 to 0.08   |
| Caregiver education                    | 0.09  | 0.03 | 0.09      | 0.006** | 0.01 to 0.15    |
| Care recipient race                    | 0.20  | 0.21 | 0.04      | 0.34    | -0.20 to 0.60   |
| Care recipient sex                     | 0.27  | 0.23 | 0.04      | 0.26    | -0.17 to 0.69   |
| Care recipient education              | -0.08 | 0.04 | -0.08     | 0.05*   | -0.17 to 0.00   |
| Severity (cognitive screening)        | 0.004 | 0.004| 0.05      | 0.27    | -0.003 to 0.01  |
| Activities of daily living            | 0.13  | 0.04 | 0.22      | 0.001** | 0.08 to 0.18    |
| Verbally agitated behaviors           | 0.16  | 0.02 | 0.40      | 0.001** | 0.12 to 0.20    |
| Physically aggressive behaviors       | 0.06  | 0.09 | 0.03      | 0.51    | -0.12 to 0.23   |
| Physically non-aggressive behaviors   | -0.003| 0.02 | -0.01     | 0.84    | -0.04 to 0.03   |

Note: ZBI, Zarit Burden Interview; CMAI, Cohen Mansfield Agitation Inventory. *\(P < 0.05\); **\(P < 0.01\).
dementia, Lewy Body Dementia). The current sample of individuals presenting for an appointment at an outpatient memory clinic was comprised of largely community-dwelling individuals and did not restrict diagnoses. The three dimensions of agitation detected in this sample thus appear to apply across levels of care and diagnoses.

Caregiver burden was significantly associated with agitation, and specific types of agitation were related to certain components of caregiver burden. Findings enhance understanding of the relationships between specific agitation symptoms and distinctive aspects of caregiver burden, suggesting that targeted interventions for various aspects of caregiver burden based on specific symptoms may be useful in alleviating burden. A recent meta-analysis of interventions addressing caregiver burden found that multi-component interventions involving psychoeducation, coping strategies, cognitive reappraisal, and emotional support were most effective in alleviating burden. A review of interventions for alleviating agitation behaviours in dementia found some evidence for pharmacological intervention, psychosocial interventions (e.g., instrumental assistance, psychoeducation), nursing care, physical activity, and patient-centred care (e.g., validation, reality orientation, psychotherapy) in alleviating agitation and other behavioural symptoms in dementia. However, significant heterogeneity in interventions for care recipient agitation and caregiver burden presents a challenge for interpreting these results. Future research could explore whether components of these interventions can be tailored to the individual based on demonstrated efficacy with specific aspects of caregiver burden and/or agitation-related behaviours. For example, when the care recipient presents with physically aggressive behaviours (e.g., hitting, throwing things, grabbing people), helping the caregiver cope with embarrassment or anger at the care recipient, or with strain placed on other relationships, may be of benefit. In contrast, interventions focused on caregivers’ personal health decline, lack of time for themselves, feelings of guilt, and fear and uncertainty about the future may be most effective when care recipients present with physically non-aggressive behaviours (e.g., pacing, restlessness, inappropriate dress or disrobing). When a care recipient presents with verbally agitated behaviours, interventions targeting caregiver burden more globally may be necessary. Tailoring interventions in this manner might enhance effectiveness in alleviation of burden, while also reducing agitation behaviours in the care recipient, and ultimately decreasing the complexity and cost of interventions.

Inclusion of a range of dementia spectrum diagnoses and exploration of these relationships in an outpatient clinic sample are strengths of the current study. However, limitations are present, which may impact generalizability to other populations. The clinic sample largely consisted of white, adult children of the care recipient, reflected in the average age of caregivers (63 years). Additionally, caregivers had, on average, received a college education. As prior work indicates relationships between caregiver burden and gender, age, education, relationship to the care recipient, and race, these variables were controlled for in analyses. However, to improve generalizability, future work should explore these links in a more diverse sample, perhaps with a greater proportion of spouses of the care recipient providing care, as the association between agitation and specific domains of burden may change with age or nature of the relationship. Additionally, findings could differ in a sample that has a larger proportion of care recipients with behavioural disturbance as a primary characteristic of the subset of dementia, such as frontotemporal dementia; however, as the current study examined continuously enrolled care recipients of a memory clinic, these findings may be representative of that setting. Future research should explore the relationships between agitation and caregiver burden in larger samples that can be stratified by dementia classification in order to compare subtypes. Finally, low frequency agitation behaviours were excluded in the current study due to emphasis on factor analysis. However, even if infrequently occurring, those behaviours (e.g., spitting, biting, making physical and verbal sexual advances) likely still pose challenges to caregivers. Future work should explore the relationships between these less common symptoms and caregiver burden.

In conclusion, findings from the current work suggest that different facets of agitation in dementia may differentially contribute to specific aspects of caregiver burden. Future work should explore whether interventions targeting specific aspects of caregiver burden are effective in alleviating burden, depending
on the care recipients’ specific agitation-related behaviours.

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DATA AVAILABILITY STATEMENT
The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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