Prevalence of and associations with agitation in residents with dementia living in care homes: MARQUE cross-sectional study

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Background
Agitation is reportedly the most common neuropsychiatric symptom in care home residents with dementia.

Aims
To report, in a large care home survey, prevalence and determinants of agitation in residents with dementia.

Method
We interviewed staff from 86 care homes between 13 January 2014 and 12 November 2015 about residents with dementia with respect to agitation (Cohen-Mansfield Agitation Inventory (CMAI), quality of life (DEMQOL-proxy) and dementia severity (Clinical Dementia Rating). We also interviewed residents and their relatives. We used random effects models adjusted for resident age, gender, dementia severity and care home type with CMAI as a continuous score.

Results
Out of 3053 (86.2%) residents who had dementia, 1489 (52.7%) eligible residents participated. Fifteen per cent of residents with very mild dementia had clinically significant agitation compared with 33% with mild (odds ratios (OR)=4.49 95% confidence interval (CI)=2.30) and 45% with moderate or severe dementia (OR=6.95 95% CI=3.63, 13.31 and OR=6.23 95% CI=3.25, 11.94, respectively). More agitation was associated with lower quality of life (regression coefficient (rc)=−0.53; 95% CI=−0.61, −0.46) but not with staffing or resident ratio (rc=0.03; 95% CI=−0.04, 0.11), level of residents’ engagement in home activities (rc=3.21; 95% CI=−0.82, 7.21) or family visit numbers (rc=−0.03; 95% CI=−0.15, 0.08). It was correlated with antipsychotic use (rc=−6.45; 95% CI=3.98, 8.91).

Conclusions
Care home residents with dementia and agitation have lower quality of life. More staffing time and activities as currently provided are not associated with lower agitation levels. New approaches to develop staff skills in understanding and responding to the underlying reasons for individual resident’s agitation require development and testing.

Declaration of interest
None.

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Agitation is often considered a symptom of distress in people with dementia, leading to family distress and burden. It accounts for about 12% of health and social care costs for people with dementia. Agitation refers to a range of behaviours including restlessness, pacing, repetitive vocalisations and verbally or physically aggressive behaviour. It is the most common neuropsychiatric symptom, and it is more persistent when more severe. In community settings, its prevalence increases with dementia severity. Prevalence is around 10% in people with mild cognitive impairment, 15% in people with dementia presenting to memory clinics and 30% in those living in the community.

Many people with dementia and agitation are admitted to care homes, with the relationship between agitation and admission mediated by carer distress. Although we may, therefore, expect many residents of care homes to be agitated, there have been no large, representative studies to determine whether this is the case, or how agitation levels relate to dementia severity in care homes. In a UK survey of 233 care home residents, agitation was the most common clinically significant neuropsychiatric symptom, with 40% of participants experiencing some symptoms. In the largest care homes study of agitation to date, among 1322 people with dementia in 59 units in the Netherlands, 85% showed at least one symptom of agitation, most frequently general restlessness. Physical aggression was more common in people with very severe dementia, and disinhibition, irritability and verbally agitated behaviours were more common in moderate dementia. Agitation has been associated with lower quality of life in small care home studies.

Symptoms of agitation are often conceptualised as arising from unmet need in a person unable to identify, communicate and respond to their own needs, who also has brain pathology predisposing to disinhibition and repetitive behaviour. This model is supported by findings from small randomised controlled trials that activities, sensory interventions, structured music therapy and interventions to improve staff communication, prevent or reduce agitation. Nonetheless, there is no good evidence that care home residents with dementia are less agitated or have a higher quality of life, when they have access to more activity or social interaction (from family visits or a higher number of staff). This is particularly important given the need to provide ways to manage agitation alternative to antipsychotic prescribing, levels of which may now be steady, despite initiatives to reduce their use.

This is the largest study of residents with dementia in care homes to date. Our primary aim is to discover how common clinically significant agitation is and test our hypothesis that in residents with dementia, higher levels of agitation are associated with lower quality of life. Our secondary hypotheses from the literature above suggesting that agitation is caused by dementia and unfulfilled needs in terms of less social interaction, stimulation and activity are that agitation is associated with: (1) more severe dementia, (2) fewer staff numbers per resident, (3) fewer family visits and (4) lower care home activity levels. We will also explore the relationship of agitation to psychotropic medication prescription and care home environment.
Method

This study reports the Managing Agitation and Raising QUALity of lifE in dementia (MARQUE) longitudinal care home study baseline findings. It received ethical approval from the London (Harrow) NRES Committee (14/LO/0034).

Setting and sampling

We recruited care homes across England. Our sampling frame comprised each provider type (voluntary, state and private), care provision (nursing, residential) and reflected English care home provision where people with dementia resided to ensure external validity and generalisability. We defined care home clusters as units within care homes in which staff and managers worked separately. If staff in units cross-covered each other we defined this as one cluster.

Procedures

We recruited through third sector partners, NHS trusts and clinicians, a Department of Health newsletter and the NIHR Clinical Research Network. We sought care home managers’ agreement for each home’s inclusion. Each manager provided a staff list and identified residents with a known clinical dementia diagnosis. Care home staff completed the Noticeable Problems Checklist (NPC) for all residents without a known diagnosis of dementia, to identify those with probable undiagnosed dementia. The NPC is a six-item questionnaire covering memory, basic self-care, orientation, naming familiar people and ability to follow conversations, which has been used by non-clinicians and which has been validated against clinical diagnosis. Eligible participants were all residents with an existing dementia diagnosis or those who screened positive for dementia, and their family and care home staff.

Staff asked residents, whom they judged as having decisional competence for consent, if researchers could approach them. Residents who had decisional competence for consent were asked for written informed consent to the study. Consultees were asked to make this decision for those lacking capacity in line with the Mental Capacity Act (2005). For all other residents, the staff tried to contact the next-of-kin (to participate in family carer interviews) and asked if the researchers could contact them. Participating staff and relatives gave written informed consent. We asked a staff member working closely with each resident with dementia to rate proxy measures for the resident and then asked the relative to do the same. In addition, all consenting staff providing hands-on care completed questionnaires about themselves as did consenting relatives. All participants were recruited between 13 January 2014 and 12 November 2015.

Measures

Trained research assistants interviewed staff and residents in a private room at the care home. We interviewed family carers in their preferred location: in the care home, their own home or the researcher’s office.

Care home measures

We recorded information about the care home, including whether it was a residential or nursing home, number of residents (in total and with dementia), staff numbers, and programmed activities with number of attendees.

We used the Therapeutic Environment Screening Survey for Nursing Homes and Residential Care (TESS-NH/RC), which has satisfactory psychometric properties, to rate the care home’s physical environment. The TESS sums 15 environmental items, each scoring from 0 to 2 (facility maintenance, cleanliness, handrails, call buttons, light intensity, light glare, light evenness, hallway length (shorter is better), homeliness, room autonomy, the presence of telephones, tactile stimulation, visual stimulation, privacy and outdoor areas) into the Environmental Quality Score (EQS). Higher scores indicate better environmental quality.

Residents measures

We recorded demographic information and completed the following measures:

1. Agitation: our primary outcome was the Cohen-Mansfield Agitation Inventory (CMAI), a 29-item questionnaire with construct validity and reliability to measure agitation in people with dementia in care homes. The CMAI is an informant questionnaire and each item scores from 1 to 7, with 1 meaning ‘never’ and 7 ‘several times per hour’. The score sums individual items and ranges from 29 to 203. A score of >45 is usually regarded as clinically significant agitation.

2. Quality of life: The DEMQOL and DEMQOL proxy are responsive, valid and reliable measures of quality of life in people with dementia. The DEMQOL-Proxy is a 31-item interviewer-administered questionnaire answered by a professional or family carer. The people with dementia who were able to were asked to complete the DEMQOL, a 28-item interviewer-administered questionnaire. As the DEMQOL has fewer questions than the DEMQOL proxy, the totals are not directly comparable.

3. Dementia severity: Staff gave information so the researcher could rate the severity of dementia by the Clinical Dementia Rating (CDR). This is a reliable and valid instrument for rating severity of dementia. It is used to rate performance in memory, orientation, judgment and problem-solving, community affairs, home and hobbies, and personal care, and this information was used to classify dementia severity of included residents into very mild, mild, moderate or severe.

4. Neuropsychiatric symptoms: the Neuropsychiatric Inventario (NPI) is a validated instrument with 12 domains of neuropsychiatric symptoms, including agitation. Each domain scores between 0 and 12 with higher scores meaning increasing severity. A score of ≥4 on any domain is usually considered clinically significant severity. A summed score can be calculated for total neuropsychiatric symptoms.

Staff self-rated measures

Staff working in the care home provided their demographic details and working patterns.

Family carer measures

We asked relatives visiting residents at least monthly to complete the DEMQOL-proxy and tell us how often they visited. We recorded their gender and relationship to the person with dementia.

Analysis

We used Stata version 14 for all analyses. Characteristics of care homes and people with dementia, including CMAI scores and presence of significant agitation, are summarised by frequency (%) mean (standard deviation (s.d.)) or median (interquartile range (IQR)) as appropriate. To obtain values more relevant to the types of care home in England, we weighted estimates, using population

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information about the distribution of care home types (nursing or residential and private sector or voluntary, local authority (LA) and National Health Service (NHS)). Probability weights were based on available figures in England from the Care Quality Commission (CQC) from 31 December 2012. At this time, 73% of the total 17 592 care homes were residential homes. The remaining 27% were either nursing homes or both nursing and residential. Seventy-five per cent of care homes in England were private whereas 25% were ‘voluntary’ (non-profit sector), LA or NHS. In calculating the weights, we assumed that the percentage of residential and nursing homes was the same within the private sector and voluntary, LA and NHS.

To investigate our primary and secondary hypotheses, we used random effects models to account for care home or unit clustering and adjusted for residents’ age, gender, CDR dementia severity and care home type (residential or nursing or both, dementia specialist, dementia registered). For the primary hypothesis, we also fitted a three-level model accounting for clustering by staff member, as some provided information about multiple residents in the home. We carried out analyses with CMAI as a continuous score. As we found some skewness in model residuals for this outcome, we checked results in sensitivity analyses based on generalised linear models with a gamma distribution. In further sensitivity analyses, we fitted models with CMAI as two groups defined by presence of clinically significant agitation (CMAI>45). Again we controlled for residents’ age, gender, dementia severity, care home type (residential, nursing or both, dementia specialist, dementia registered). We also carried out an additional sensitivity analysis with significant agitation defined by the NPI agitation domain score (significant agitation is a score ≥4) in place of CMAI.

Study participation

Out of the 114 care homes we contacted, 86 (75.4%) participated. Of the 28 who did not participate, 21 were nursing or mixed nursing and residential and 7 were residential only. Among the 28 care homes, 22 did not wish to participate, 5 were too busy or had a new manager and 1 was excluded as in another research project. We therefore recruited 86 care homes: 7 homes were divided into >1 cluster, totalling 18 clusters. The sample, therefore, was 97 clusters.

Our flow diagram (Fig. 1) shows residents’ recruitment to the study. After considering pre-existing clinical dementia diagnosis and those who screened positive on the NPC, 3053 (86.2%) residents within the care homes had probable dementia and thus were eligible. Out of the 2825 residents who were approached, 1489 (52.7%) participated. The common reasons for non-participation were refusal (27.3%) and staff being unable to contact the family consultee (17.6%). Of the participating residents, 300 (20.1%) had capacity to consent to the study and we used a consultee for the remainder. We have no data for six residents for whom we had consent, as five died and one moved before data were collected, so our analyses are based on 1483 people. Out of 1483, 1281 (86.4%) had a pre-existing clinical diagnosis of dementia and the remainder scored positive on the NPC. The number of recruited residents per cluster ranged from 2 to 55 (median 14).

In total, 1281 (86.4%) of consenting residents had an identified family member who agreed to participate. A total of 1701 care home staff consented. Numbers of staff per cluster ranged from 3 to 54 (median 15). Care home and staff characteristics are summarised in Table 1.

Results

Sample characteristics

Table 2 shows recruited residents’ and relatives’ demographic characteristics. Approximately equal proportions of residents were classified as having severe, moderate, or mild or very mild dementia. Around two-thirds of identified family members were women and a similar proportion were sons or daughters. The median number of visits residents received from their main family carer was six each month.

Table 3 summarises agitation, quality of life scores and psychotropic medication. Staff and family members’ total quality of life proxy ratings were similar, however, the correlations between family- and staff-rated DEMQOL was low at 0.35. More than half the residents were prescribed psychotropic medication, most commonly antidepressants (40%).

Agitation levels and correlates

A total of 209 (14.7%) residents did not have symptoms of agitation, whereas 569 (40%) had clinically significant agitation according to CMAI and 465 (32%) on the NPI (Table 3). Fifteen (13%) of those with very mild dementia had clinically significant levels of agitation (CMAI cases). In comparison, the prevalence was higher in other CDR categories (mild dementia 102 (33%), moderate dementia 212 (45%), severe dementia 239 (45%). A random effects logistic regression model adjusted for resident’s age, gender, care home type (residential, nursing or both, dementia specialist, dementia registered) showed significantly greater odds of CMAI caseness in participants with mild, moderate and severe compared with very mild dementia. (odds ratios (ORs): mild dementia 4.49, 95% confidence interval (CI)=2.30 to 8.74; moderate dementia 6.95, 95% CI=3.63 to 13.31; and severe dementia 6.23, 95% CI=3.25 to 11.94).

Average CMAI score in those with very mild dementia was 37.0, s.d.=10.4, which was lower than other CDR categories (mild 43.5, s.d.=15.6; moderate 48.7, s.d.=19.0; severe 48.3, s.d.=19.7). A random effects model adjusted for resident’s age, gender, care home type (residential, nursing or both, dementia specialist, dementia registered) indicated significant CMAI differences between very mild and other CDR categories (mild dementia coefficient 7.35, 95% CI=3.55 to 11.44; moderate dementia 11.04, 95% CI=7.34 to 14.71; severe dementia 9.70, 95% CI=6.01 to 13.39).

Higher agitation levels were significantly associated with lower staff and family ratings of the resident’s quality of life, and with prescription of antipsychotics and hypnotics but not analgesics or antidepressants (Table 4). Agitation levels were not associated with frequency of family visits, time spent in activities per resident, staff ratios, number of residents or quality of the environment.

Sensitivity analyses

Sensitivity analyses based on agitation caseness showed exactly the same pattern (Table 5) as did analyses with models based on a gamma distribution. Analyses with caseness based on NPI agitation scores also showed similar associations except increased staff numbers and staff/resident ratios were associated with increased resident agitation (adjusted analysis for higher staff numbers to NPI agitation caseness, OR=1.010 (95% CI 1.003, 1.017)) (Table 6). The significant relationship with staff-rated quality of life was also maintained in a three-level model incorporating clustering by staff member (adjusted regression coefficient −0.53, 95% CI: −0.61 to −0.46). Information about the number of family visits each month was missing for 15% of people. A sensitivity analysis assuming this equated to no visits did not change the results.
Discussion

We found that 86% of care home residents had dementia. Of those, 40% had clinically significant agitation symptoms and 86% had some symptoms. Those who were agitated had a lower quality of life as rated by staff and family carers, confirming our hypothesis that agitation in care home residents with dementia is associated with lower quality of life. Earlier studies had suggested that there may be relationship but a recent systematic review found there was insufficient available evidence to draw conclusions.20,21,41

Agitation in care home residents is, as in the community, associated with more severe (as opposed to very mild) dementia. This relationship is not linear, with 45% of those with both moderate and severe dementia having clinically significant agitation. This indicates that agitation is not wholly a symptom of worsening brain pathology or it would parallel cognition in its severity. The high prevalence of agitation in care homes probably relates to the greater likelihood of people with agitation moving to a care home and the high prevalence of moderate and more severe dementia within care homes, as well as a lack of effective strategies to manage it.

Fig 1 MARQUE baseline flow diagram of recruited residents.
difficulty knowing or conveying what they need, and to identify the needs of individual agitated residents.

In a cross-sectional study, the number of family visits a month may reflect a resident’s needs, with relatives visiting more when a resident is more unwell and, conversely, with relatives visiting those who are most impaired less frequently with few perceived opportunities for communication. Individuals whose relatives have been unable to manage are more likely to be admitted to care homes and their family members are often themselves distressed. Seeing family can trigger feelings of loss, particularly when they are used less. However, we report higher rates of antipsychotics prescriptions compared with the 2010 report. Both these trends are consistent with international studies.

We did not find a link between the quality of the environment (measured by the TESS in our study) and quality of life. Surprisingly, the one other study to investigate this found that quality of life was negatively associated with a good environment. Thus a good environment may not be enough to improve quality of life. An improved environment may be of little benefit to some individuals, especially if they remain in one room of the care home and do not routinely access the better space, the outdoors and natural light.

Table 1 Care home or unit and staff characteristics (numbers are frequency (%) unless stated otherwise)

| Care homes or units characteristic n=97 | Unweighted | Weighted for England* |
|----------------------------------------|------------|-----------------------|
| Home or unit type                       |            |                       |
| Nursing                                | 13 (13%)   | 5%                    |
| Personal care (residential)            | 39 (40%)   | 73%                   |
| Nursing and personal care              | 45 (46%)   | 22%                   |
| Dementia registered home               | 86 (89%)   | 88%                   |
| Dementia specialist home               | 42 (43%)   | 45%                   |
| Environmental quality score (TESS) mean (s.d.) n=86 | 14 (3) | 16 (2) |
| Care home activity participation (hours per person per week) median (IQR) n=89 (range: 0.30-18.87 hours) | 2.07 (1.43, 3.08) | 2.15 (1.40, 3.70) |
| Total number of resident places in the home median (IQR) | 38 (27, 54) | 36 (26, 51) |
| Total permanent nursing and care staff in previous week median (IQR) n=96 | 32 (20, 50) | 27 (16, 42) |
| Staff/resident ratio mean (s.d.) n=96 | 1.1 (1.22) | 1.1:08 (1:2) |
| Staff                                  |            |                       |
| Staff works days only n=1693           | 1150 (68%) | 68%                   |
| Staff works any other shift pattern n=543 (32%) | 32% |

IQR, interquartile range.

a. For the MARQUE cohort, 28 care homes were private residential, 50 private nursing or nursing and residential, 11 non-private residential and 8 non-private nursing or nursing and residential. Probability weights were calculated as number of care homes in the given category in England or number of care homes in the same category in MARQUE.

Table 2 Sociodemographic characteristics of baseline MARQUE cohort (Numbers are frequency (%) unless otherwise stated)

| Resident characteristic | Unweighted | Weighted for England* |
|-------------------------|------------|-----------------------|
| Male n=1483             | 457 (31%)  | 28%                   |
| Age, years: mean (s.d.) n=1437 | 85 (9) | 86 (8) |
| Ethnicity n=1452        |            |                       |
| White British           | 1281 (88%) | 91%                   |
| White Irish             | 43 (3%)    | 2%                    |
| White other             | 50 (3%)    | 3%                    |
| Black British, Caribbean, African | 33 (2%) | 2%        |
| Asian or Asian British, Indian | 13 (1%) | 0.5% |
| Pakistani, Bangladeshi  |            |                       |
| Mixed: White and Black Caribbean | 1 (0.1%) | 0.03% |
| Chinese                 | 2 (0.1%)   | 0.1%                  |
| Other                   | 29 (2%)    | 2%                    |

Dementia severity (CDR) n=1458

| Very mild               | 114 (8%)   | 10%                   |
| Mild                    | 313 (21%)  | 23%                   |
| Moderate                | 482 (33%)  | 33%                   |
| Severe                  | 549 (38%)  | 34%                   |

Family member characteristic

| Male n=1102             | 341 (31%)  | 32%                   |
| Age, years: mean (s.d.) n=1048 | 63 (11) | 63 (11) |
| Relationship n=1101     |            |                       |
| Spouse                  | 209 (19%)  | 15%                   |
| Son or daughter         | 674 (61%)  | 65%                   |
| Son or daughter-in-law  | 28 (3%)    | 2%                    |
| Grandchild              | 15 (1%)    | 2%                    |
| Friend                  | 38 (3%)    | 3%                    |
| Other                   | 137 (12%)  | 13%                   |

Number of family visits per month: median (IQR) n=1243

| 6 (3, 13) | 4 (2, 13) |

CDR, Clinical Dementia Rating; IQR, interquartile range.

a. For the MARQUE cohort, 28 care homes were private residential, 50 private nursing or nursing and residential, 11 non-private residential and 8 non-private nursing or nursing and residential. Probability weights were calculated as number of care homes in the given category in England or number of care homes in the same category in MARQUE.
This study is large and weighted for representativeness; it covered varied homes throughout England and was planned to ensure external generalisability. Sensitivity analyses found the same results. Most homes approached agreed to participate. It may, however, be that homes which feel more confident about being scrutinised are more likely to agree to research and those residents or their families who refused participation or who could not be contacted were more agitated or had more severe dementia. A slightly higher proportion of nursing homes refused to participate. We may, therefore, have underestimated the prevalence of agitation, although our figures are similar to those in previous studies.8,17

### Table 3: Resident agitation, quality of life and medication (numbers are frequency (%)) or median (IQRI)

| Resident characteristic Unweighted | Weighted for England |
|------------------------------------|-----------------------|
| Agitation                          |                       |
| CMAI total n=1424                 | 569 (40%) 41%         |
| CMAI n=1424                       | 41 (33, 55) 41 (32, 56) |
| NPI                                |                       |
| Positive NPI agitation n=1450      | 833 (57%) 57%         |
| NPI agitation frequency* severity  | 465 (32%) 31%         |
| 4+ n=1449                          |                       |
| Quality of life (DEMQOL)           |                       |
| Resident completed n=482           | 92 (80, 101) 94 (83, 102) |
| Staff proxy n=1455                 | 104 (95, 110) 104 (95, 111) |
| Family proxy n=1054                | 101 (90, 109) 102 (90, 109) |

Medication prescribed n=1483

- Any psychotropic medication a 825 (56%) 54%
- Antipsychotics 248 (17%) 15%
- Antidepressants 587 (40%) 39%
- Anxiolytics or hypnotics a 285 (19%) 18%
- Analgesia 961 (65%) 64%

CMAI, Cohen-Mansfield agitation inventory; IQRI, interquartile range. a. Any of antipsychotics, antipsychotics, hypnotics or anxiolytics. b. Not including melatonin as not classed as a psychotropic drug (16 residents were prescribed melatonin).
We conclude that most residents in care homes have dementia and many are agitated with low quality of life. This indicates that new interventions are needed to reduce agitation. For those persons with dementia, agitation and a lowered quality of life, our findings from this survey suggest that investing in more of the current systems of care (increasing staff to resident ratios and activities within the care home and improving the environment) are unlikely to be sufficient to reduce agitation. We suggest that future research should focus on applying personalised approaches to managing agitation in residents with dementia, while also determining which specific individualised activities would be of greatest benefit. Tools should be provided for staff to understand, communicate with and engage individual residents to enable them to analyse the underlying reasons for agitation, which may include pain, discomfort, loneliness and boredom. This would enable care homes to deliver personalised interventions to reduce agitation and increase quality of life of their residents.

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