Objective: As not speaking English as a first language may lead to increased difficulties in communication with staff and other residents, we (1) tested our primary hypotheses that care home residents with dementia speaking English as a second language experience more agitation and overall neuropsychiatric symptoms, and (2) explored qualitatively how staff consider that residents’ language, ethnicity, and culture might impact on how they manage agitation.

Methods: We interviewed staff, residents with dementia, and their family carers from 86 care homes (2014–2015) about resident’s neuropsychiatric symptoms, agitation, life quality, and dementia severity. We qualitatively interviewed 25 staff.

Results: Seventy-one out of 1420 (5%) of care home residents with dementia interviewed spoke English as a second language. After controlling for dementia severity, age, and sex, and accounting for care home and staff proxy clustering, speaking English as a second language compared with as a first language was associated with significantly higher Cohen-Mansfield Agitation Inventory (adjusted difference in means 8.3, 95% confidence interval 4.1 to 12.5) and Neuropsychiatric Inventory scores (4.1, 0.65 to 7.5). Staff narratives described how linguistic and culturally isolating being in a care home where no residents or staff share your culture or language could be for people with dementia, and how this sometimes caused or worsened agitation.

Conclusions: Considering a person with dementia’s need to be understood when selecting a care home and developing technology resources to enable dementia-friendly translation services could be important strategies for reducing distress of people with dementia from minority ethnic groups who live in care homes.

KEYWORDS agitation, care home, dementia
INTRODUCTION

Around 850,000 UK people live with dementia, and this is expected to be over 1 million by 2025. The number of people from Black and Minority Ethnic groups (BME) with dementia in England is projected to increase 7-fold in the next 40 years. At least two thirds of care home residents have dementia. People with dementia from some BME groups are less likely to move to a care home than those from the white majority population. Possible explanatory factors include expectations among family carers that services will be culturally inappropriate (in terms of language and food), and a greater sense of filial piety and obligation. Care home staff have reported challenges providing culturally appropriate care, for example appropriate diets and translation services, and in day to day communication. With the number of BME care home residents with dementia projected to increase due to demographic trends, it is important to consider how care homes can best provide culturally competent care.

In people with dementia, language impairment can impede functioning and effective communication, resulting in disruptive behaviour due to unmet needs or frustration. Residents with dementia may become agitated if people use language beyond their comprehension or they are not understood when communicating. Language impairment may be especially challenging for people whose first language is not the local language, in whom cognitive decline can cause regression to the primary language, and loss of second language abilities.

The MARQUE (Managing Agitation and Raising Quality of life) study includes the largest ever study of care home residents with dementia, the first to compare experiences of people with dementia who do and do not speak English as a first language. As not being a native speaker may lead to difficulties communicating with staff and other residents, we tested our primary hypothesis that care home residents with dementia speaking English as a second language experienced more neuropsychiatric symptoms, including agitation than those speaking English as a first language. Our secondary hypothesis was that compared with those speaking English as a first language, care home residents with dementia speaking English as a second language had more severe dementia, because they entered care homes later in the illness due to a range of barriers to access or family structure allowing them to be supported at home. We also interviewed care home staff qualitatively to explore how they consider residents’ language, ethnicity, and culture to affect how they manage agitation symptoms.

METHODS

Harrow (14/LO/0034) and London (Queen’s Square) (14/LO/0697) National Research Ethics Service (NRES) committees approved the quantitative and qualitative studies respectively. All staff and family carer participants gave informed consent before participating.

2.1 Setting and sampling

We recruited care homes across England, of each provider type (voluntary, state, and private), care provision (nursing, residential), and urban/suburban and rural locations, from July 2014 to October 2015.

2.2 Procedures

We recruited homes through third sector partners, NHS trusts, Care England newsletter, and the NIHR Clinical Research Network. We divided care homes into clusters, defining clusters as units within care homes. Most units comprised 1 whole care home, but where care homes operated as distinct units with discrete staff groups (for example, residential care and nursing care units operating as distinct entities), 1 care home was considered as 2 or 3 units. If staff cross-covered between units, we defined this as 1 cluster.

We sought care home managers’ agreement for their home’s inclusion. In included homes, all consenting regular staff who provided hands-on care were asked to complete measures. A senior staff member identified residents with a dementia diagnosis and for others completed the Noticeable Problems Checklist with care home staff to detect residents with undiagnosed probable dementia. We asked the paid carer working most closely with each resident with dementia, and their family carer if they visited at least once a month to complete proxy measures. For the qualitative interviews we purposively selected from the 86 care homes where quantitative data were collected. After initial contact with care home managers, we approached individual staff members who were involved in the day to day, “hands-on” care of participating residents to complete proxy measures. We used purposive sampling to ensure that we interviewed staff of both sexes, differing age, ethnicity, nationality, and with different roles and experience.

2.3 Quantitative measures

Trained research assistants interviewed staff in private care home rooms. We interviewed family carers in their preferred location: the care home, their own home, or the researcher’s office.
We asked managers about care home type (residential care, nursing care, or both), whether it was dementia specialist (staff had specific dementia training), and registered with regulatory authorities as providing care to people with dementia. We recorded residents’ demographic information, including whether they spoke English as a second language and ethnic group; staff completed the following proxy measures:

1. The Cohen-Mansfield Agitation Inventory (CMAI) is a 29-item informant questionnaire with construct validity and reliability to measure agitation in people with dementia in care homes (32;33). Each item scores from 1 meaning “never” to 7 “several times per hour”. The score sums individual items. A score of >45 is usually regarded as clinically significant agitation (34).

2. The DEMQOL proxy is a responsive, valid, and reliable interviewer-administered measure of quality of life in people with dementia (35;36).

3. Staff gave information so the researcher could rate dementia severity using the Clinical Dementia Rating (CDR) (37). This is reliable and valid (38). It is used to rate performance in Memory, Orientation, Judgment and Problem solving, Community Affairs, Home and Hobbies, and Personal Care. This information was used to classify dementia severity as very mild, mild, moderate, or severe.

4. The Neuropsychiatric Inventory (39) 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 summed score is calculated for total neuropsychiatric symptoms (14).

We asked relatives visiting residents at least monthly to complete the DEMQOL-proxy (36).

2.4 | Qualitative interviews

PR conducted qualitative interviews in private rooms in care homes with staff who gave written, informed consent. We developed our semi-structured interview schedule around our study aim to understand how staff managed agitation, using research literature, consultation with family carers of people with dementia, and research team expert opinion. We elicited staff perceptions using open-ended questions and revised questions iteratively, exploring issues raised. We continued interviewing until we reached theoretical saturation. Interviews were audio-recorded and transcribed verbatim.

2.5 | Analysis

We used Stata version 14 for all quantitative analyses (40). Characteristics of care homes and people with dementia are summarised using frequency (%), mean (standard deviation), or median (interquartile range) as appropriate. To investigate our hypotheses, we used random effects models to account for care home/unit clustering and clustering by paid carer, as some paid carers provided information about multiple residents in the home. We adjusted for resident’s age, sex, dementia severity, and care home type (residential/nursing/both, dementia specialist, dementia registered).

We used NVivo software for qualitative data analysis and took a thematic analytic approach.13 PR and a second, independent rater (CC) systematically coded the transcripts into meaningful fragments and labelled these initial codes. Discrepancies were discussed and resolved. PR and CC then organised the data into preliminary themes. We discussed the coding frames within the team using the constant comparison method to identify similarities and differences in the data.

3 | RESULTS

3.1 | Quantitative

Eighty-six out of 114 (75.4%) of the care homes we contacted participated. Of the 28 who did not participate, 21 were nursing or mixed nursing and residential and 7 residential only. Twenty-seven declined to participate, and 1 was excluded as they were taking part in another research project. We recruited 86 care homes; 7 homes were divided into >1 cluster, totalling 18 clusters. The sample, therefore, was 97 clusters.

Seventy-one out of 1420 (5%) care home residents with dementia in our study spoke English as a second language; 37 (38%) of care home units were home to residents speaking English as a second language: 23 were home to only 1 resident, and the remainder were home to between 2 and 5 residents speaking English as a second language.

Tables 1 and 2 show the demographic, illness, and care home characteristics of residents speaking English as a first or second language, including information on missing data. As hypothesised, agitation and neuropsychiatric symptom levels were higher in those speaking English as a second language relative to those who were native speakers. After controlling for dementia severity, resident age, and sex and accounting for care home and staff proxy clustering, speaking English as a second language was associated with significantly higher CMAI (adjusted difference in means 8.3 (95% confidence interval [CI] 4.1 to 12.5) and neuropsychiatric inventory (4.1, 95% CI 0.65 to 7.5)) scores compared with those who were native speakers. These results were unchanged by controlling for care home type and dementia registration or specialism (Table 2) (8.4 [95% CI 4.2 to 12.6] and 4.1 [95% CI 0.64 to 7.5], respectively). For the CMAI (standard deviation 18.3), the effect size was 0.45.

Staff rated the quality of life of people speaking English as a first and second language similarly, while there was a trend towards lower family carer proxy ratings for people speaking English as a second language (Mann Whitney U test z = −1.9, P = 0.06). Contrary to our hypothesis, levels of dementia severity of residents speaking English as a first or second language were very similar (Table 1).

3.2 | Qualitative

PR interviewed 25 staff in 6 care homes; London (4 homes), Kent (1 home), and Cambridge (1 home). Five of the care homes were privately run, and 1 was run by a charity. Three were nursing homes, 2 residential homes, and 1 provided residential and nursing care. Table 3 summarises staff socio-demographic and employment status.

We identified 3 main themes. These were language barriers increase resident’s agitation and staff and resident’s distress, difficulties in meeting residents’ unmet cultural needs, and overcoming barriers—finding shared language and understanding. We illustrate these themes with quotes later.
3.2.1 Language barriers increase resident agitation and resident and staff distress

Several staff described how residents unable to communicate in English often became frustrated and agitated, when they could not express themselves or if they were unable to understand what was happening, for example during personal care:

*Sometimes he’s speaking his own language as well, which we don’t understand, and he’s crying, and it’s difficult when we don’t understand his language..., you know?* (Female care assistant 1, CH1)

Staff described how residents had lost their English because of the dementia and how frustrating it was when struggling to respond and reduce distress:

*Because of the dementia, they tend to become like a child again, they go back to their first or their original... language. What they start saying is something that nobody understands, and that is dementia, they become*...

(Female care assistant 1, CH1)

3.2.2 Difficulties in meeting residents unmet cultural needs

Staff highlighted how they sometimes struggled to connect with, understand, and respond to residents’ cultural needs. A care assistant described how a resident’s agitation seemed to relate to an unmet spiritual need:
approaches: communicate, by learning a few shared words or using non

Other staff explained that they would try and find creative ways to

mental to resolving an episode of agitation:

It was sometimes unclear how well information about residents' social

and cultural backgrounds was shared and used within homes:

I saw her care plan, where she worked, she was born in

India, she was brought up for 35 years in Bombay, she

speaks Hindi, I've never spoken to her in English, we

together speak Hindi, then my manager was asking, can

she speak Hindi? She was surprised. (Female senior
carer, CH3)

3.2.3 | Overcoming barriers—finding shared language and understanding

Staff recounted how agitated residents became calmer and more

engaged when staff fortuitously shared their language or culture, or a

friend or family member visited:

...her daughter was there, ...then the menu was there, she

said, I'm fed up with this food; then I asked her in the

Indian language, her daughter doesn't understand

because she was born here and brought up here, but her

mother speaks it, then I gave her so many menu lists , ... her

favourite dishes are masa dosa and pani poori.

(Female senior carer, CH3)

...sometimes he points, like, you know, stomach. If you ask

him, like, what’s wrong with you, he will speak in his

language, but he will point. (Female care assistant 1, CH1)

4 | DISCUSSION

We confirmed our primary hypothesis that care home residents with
dementia speaking English as a second language experienced more agi-
tation and neuropsychiatric symptoms than those speaking English as a
first language. These differences were not because they were living in
the care homes later in their illness than those speaking English as a
first language, because the severity of their dementia was not greater
than those who spoke English as a first language. Most of the residents
speaking English as a second language had clinically significant agita-
tion levels, and the effect size we found (0.45) suggests that the
increase in agitation in this group is likely to be clinically important.

In our qualitative interviews, staff spoke of the difficulties caring
for residents with dementia when they did not share a language.
Where possible, they found staff or relatives with the appropriate
language skills, and otherwise managed as best they could through
non-verbal communication or learning a few words of the resident's
language. Without a shared language, agitation was more difficult to
manage and resolve. None of the staff mentioned access to profes-
sional translators, other cultural or language resources, or training they
had received.

We have previously reported from the MARQUE study that agita-
tion is associated with lower life quality. Family carers rated quality
of life of residents speaking English as a second language lower, rela-
tive to those speaking English as a first language. For staff proxy raters,
we did not find this difference. As family carers are more likely to share
a language and culture with the resident compared with staff, this
could indicate that staff underestimate the extent or impact of agita-
tion where there are language or cultural barriers. We hypothesised
that agitation and neuropsychiatric symptoms would be greater in peo-
ple speaking English as a second language because there would be
more language barriers preventing them from living well with dementia
and receiving good care. Language barriers have been cited previously
as a cause of reduced satisfaction with health or social care services.

Interventions have successfully increased person-centred care in
care homes, through training carers to increase the quantity and
quality of their verbal communication with residents, especially around
personal care (ref Bourgeois). It was clear from staff narratives that
residents with dementia speaking no English, who were losing their
English skills or came from minority cultural groups, were often linguis-
tically and culturally isolated, unable to routinely communicate through
a common language, unless a staff member on shift fortuitously shared
their language. There is evidence that BME groups have better mental
health when living in areas with higher proportions of people of the
same ethnicity. Care homes with language or cultural specialisms
are rare, but where they exist, may be less isolating and comforting
for residents and their relatives. More may develop as the older English
BME population increases in size. Face-to-face interpreting services
are expensive and tend in our clinical experience to be reserved for
appointments with health or social care professionals. Where they
are used more frequently, it is often in response to very severe agitation. Online interpreting services or other technology solutions could reduce language barriers in care homes and, together with asking families to provide staff with a few written words of basic vocabulary and training staff to understand and address unmet socio-cultural needs, may be more feasible in the current climate of austerity. Considering whether staff speak the language and planning their shifts and using local cultural as well as individual resources could improve communication for some residents.

We cannot determine causality direction: families of participants speaking English as a second language might have had a particularly high threshold for deciding care at home was untenable, and thus this group may have had high levels of agitation at care home entry. This could explain our findings as opposed to or additional to agitation arising from greater communication difficulties experienced by non-native speakers once in the care homes. We know that BME family carers are less likely to move a relative to a care home but did not find that those in the care home had more severe dementia.

MARQUE is the largest national care home survey, but our sample was not designed to be representative. We did not evaluate English language skills of residents who were non-native speakers. These probably varied. We used language rather than ethnicity as primary outcome, as fitted our hypotheses, but these are closely related (Table 1). We cannot distinguish the impact of language, ethnicity, and culture in this study.

5 | CONCLUSIONS

Care home residents with dementia who were non-native speakers experienced more agitation and neuropsychiatric symptoms than native speakers. Staff narratives described how isolating being in a care home where no residents or staff share your culture or language could be for people with dementia, and how this sometimes increased agitation. Considering a person with dementia’s need to be understood when selecting a care home and developing dementia-friendly translation services could reduce distress for these residents. With numbers of BME people with dementia projected to rise, these are urgently needed.

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