Tamara Backhouse<sup>a</sup>, Emma Dudzinski<sup>a</sup>, Anne Killett<sup>a</sup>, Eneida Mioshi<sup>a</sup> <sup>a</sup>School of Health Sciences, University of East Anglia, Norwich, UK **Title:** Strategies and interventions to reduce or manage refusals in personal care in dementia: a systematic review

## Abstract

**Background:** Refusals of care in dementia are common and can create difficult situations for caregivers. Little is known about the best way to manage them.

**Aim:** To identify possible strategies and interventions to reduce or cope with refusals of care in dementia, and determine the evidence for these.

**Methods:** We searched MEDLINE, CINAHL, PsycINFO, EMBASE, AMED and Cochrane Central Register of Controlled Trials databases August 2018, with an updated search August 2019. An additional lateral search was conducted. Two researchers screened all records for potential eligibility and quality. Narrative synthesis was used to combine the findings.

**Results:** Out of the 5953 records identified, 36 articles, relating to 30 studies, met the eligibility criteria. Twenty-eight of the studies (93%) were set in long-term care facilities, one in a psychogeriatric unit and one with community dwelling people. Fourteen out of the 30 studies focussed on general or mixed care activities, 8 bathing, 4 mealtimes, 2 medication administration, and 2 mouth care. Strategies or interventions identified as potential ways to reduce refusals included: music interventions, interaction and communication style, caregiver approach, bathing techniques, abilities focussed approaches, distraction approaches, and video-simulated presence of a loved one. There was most evidence for music interventions and different bathing techniques, and interaction and communication styles were associated with reduced refusals. There was no evidence that slow-stroke

massage (mixed care activities) or aromatherapy (mixed care activities and medication administration) reduced refusals of care.

**Conclusions:** Some non-pharmacological interventions can reduce, but not eliminate, refusals of care, such as playing music during care or communicating positively without using elderspeak. More research evidence is needed to underpin strategies identified as encouraging such as Namaste care or distraction techniques. Future research should address gaps identified such as, the absence of research examining non-pharmacological interventions for refusals of care in hospital settings and in community settings with home-care workers, and the limited research involving family carers.

Key words (4-10): Dementia, Behaviour, Refusals, Resistance, personal care

**Tweetable abstract:** Playing music during care and offering different bathing options can reduce refusal behaviours in dementia, whereas elderspeak and negative communication are associated with refusals.

## Contribution of paper:

What is already known about the topic?

- Refusals of assistance with personal care are common in dementia, particularly in the later stages
- Refusals can be distressing to both the person living with dementia and their caregiver/s and lead to caregiver burden and crisis points
- There is limited understanding about which non-pharmacological interventions or strategies could help with refusals of care in dementia

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What this paper adds

- There is no evidence that refusal behaviours can be eliminated, but some interventions and strategies can be successful in reducing refusals.
- Playing recorded music and bathing techniques reduced instances of refusal behaviours. Interaction and communication style strategies had encouraging evidence, highlighting styles associated with refusal behaviours.
- More research is needed to obtain good quality evidence for promising interventions and to test evidenced interventions and promising strategies in hospital and family settings, including with home-care workers.

### INTRODUCTION

People with dementia develop considerable needs for assistance with their personal care, particularly at the later stages, which often surpass the demands associated with other conditions (Alzheimer's Disease International, 2015). Family carers frequently report very high levels of burden related to assisting people with dementia with their personal care due to reduced function, behaviours or incontinence (Kim et al, 2012; Zwingmann et al, 2017; Thomas et al, 2004). These issues are also a challenge for care-home staff as many people with dementia move into care homes in the later stages (Davies et al, 2012; Brodaty et al, 2014),

The considerable support needed with personal care is exacerbated when people with dementia refuse assistance with their care (Volcier, Bass and Luther, 2007), leaving those caring for them in a difficult position. Refusals (also termed resistance, rejection, non-compliance) of care occur when a caregiver approaches a person with dementia to help them and the person shows reluctance to receive assistance. This can be shown in many ways such as verbally saying no, moving away, stiffening the body, or with physical aggression. Refusals of care are different to general dementia-related behaviours such as agitation (Volicer, Bass and Luther, 2007), since they always occur as a response to caregiver actions, within an interaction. Once refusals occur, if care is not provided, the person with dementia could become neglected or receive reduced care leading to poor hygiene, urine burns, or infections (Backhouse et al, 2018<sup>b</sup>). Conversely, if care is provided, it could be against the person's will and/or restraint may be used (Backhouse et al, 2018<sup>b</sup>). Refusals of care can be due to many factors such as, the person with dementia not understanding caregiver intentions (Volicer, Van der Steen and Frijters, 2009), caregiver approach, or

unmet needs such as pain, hunger and discomfort (Ayalon et al, 2006; Edvardsson, Winblad and Sandman 2008; Galik et al, 2016; Spigelmyer, Hupcey and Kitko, 2018). Refusals of care can be difficult to manage (Backhouse et al, 2013). Therefore, assisting people with dementia with their personal care can be extremely complex and involve a high level of skill (Alzheimer's Society, 2007).

Refusals are more common in advanced dementia, than in moderate or mild (Ishii, Streim and Saliba, 2012). There are approximately 96,000 people with advanced dementia in the United Kingdom (Prince et al, 2014) and the advanced stages can last up to 40 percent of the time of the overall dementia journey (Alzheimer's Association, 2019). Refusals of care are a common occurrence from people with dementia residing in hospitals (Featherstone, Northcott and Bridges, 2019) and other institutions, with reports of 28% of nursing home residents demonstrating them (Galik et al, 2016) and in people living at home, with twothirds of informal caregivers reporting them (Fauth, Femia and Zarit, 2016). Refusals have been found to contribute to caregiver distress and overload (Fauth, Femia and Zarit, 2016; Ishii, Streim and Saliba, 2012) and crisis points leading to service use, hospitalisation or institutionalisation (Backhouse et al, 2018<sup>a</sup>; Krolak-Salmon et al, 2016; Johnson et al, 2013; Bird et al, 2007).

Given the importance of this issue and the impact on people with dementia and their caregivers, refusals are a legitimate target for intervention. Building on previous research and gaining further understanding of potential prevention strategies and interventions is vital (Volicer and Hurley, 2015) to support caregivers and improve the lives of people with dementia living in different care settings. A previous best-evidence review focussed on nursing home intervention research studies and found low evidence for music, a person-

centred approach and an ability-focused approach to reducing refusals of care (Konno, Kang and Makimoto, 2014). Our review takes a wider approach, aiming to learn from all settings and methodologies. In this systematic review, we summarize and describe possible interventions or strategies to reduce refusals of assistance with personal care in dementia and examine the evidence for their effectiveness.

#### **Review Questions**

What strategies and interventions can be used to cope with or reduce refusals of personal care in dementia? What is the evidence for these?

### METHODS

The PRISMA Guidelines were drawn on to report this review (Moher et al, 2009).

### Protocol and registration

The protocol for this review is registered on PROSPERO (Backhouse et al, 2019) (Reference CRD42019137465).

### Eligibility criteria and Information sources

We searched MEDLINE, CINAHL, PsycINFO, EMBASE, AMED and Cochrane Central Register of Controlled Trials databases for articles published up to 20<sup>th</sup> August 2018. The search strategy covered three areas: dementia, refusals and personal care (full electronic search strategy used for MEDLINE in Supplementary Material Table 8). The search was piloted and refined. To maximize the findings, there were no limitations on the searches in relation to years considered or study design. Searches were limited to humans and English language. We also conducted a supplementary lateral search using Google Scholar and reference lists of key articles. An updated search took place on 27<sup>th</sup> August 2019 to cover the preceding year.

#### Study selection process

Two authors (TB and ED) individually screened all titles for potential eligibility. Titles were excluded if they were clearly not related to dementia or refusals or if the article focussed on children or animals. All articles marked ineligible by both authors were excluded. The remaining abstracts were then screened, and relevant full texts were obtained where articles were clearly relevant or to determine eligibility. Articles were read and assessed by both TB and ED in regard to three questions for inclusion. Population: Does the article include people with dementia as participants? Condition: Does the article include information on refusals of personal care or behaviours such as agitation or aggression during, or relating directly to, personal care in dementia (isolated from other data)? Intervention/outcomes: Can we learn something about non-pharmacological strategies or interventions, which may reduce or manage refusals of care? Articles where the answer to all three questions was 'yes' were included and those with one or more 'no' were excluded. If the outcomes did not relate to refusal behaviour/aggression/agitation specifically during personal care interactions, studies were excluded. We did not exclude articles based on setting (such as hospital, family home, or nursing home) or study design; any setting and study design (except reviews) were included. Judgements were made about how the studies met the inclusion criteria, disagreements were discussed and resolved with a third author where necessary (AK).

## Data collection processes and Data items

A bespoke data extraction form guided data extraction. The extraction form included information on the authors; year; geographical location; aims of study; methods used; settings, participant group, number and demographics; dementia diagnosis, refusals, details of the intervention or strategy, personal care activity under investigation, and results. TB extracted the data. The Template for Intervention Description and Replication (TIDieR) checklist was used to extract data to describe all interventional studies (see Table 3 Supplementary data) (Hoffmann et al, 2014).

### *Risk of bias in individual studies*

We used critical appraisal tools from the Joanna Briggs Institute (see Tables 4, 5, 6 & 7 supplementary data) to assess risk of bias at study level (Joanna Briggs Institute, 2017). The different appraisal tools used, which cover internal validity (trustworthiness) and external validity (relevance) items, were matched to the relevant study design (Randomised Control Trial, Quasi-experimental, Case Report, Qualitative, and Case Control). Two authors (*TB and ED*) reviewed all articles independently against the relevant tool, dependent on study design. Disagreements were resolved through discussion and then consensus, when consensus was not reached, a third author (EM) was consulted. To control for assessment items that were not applicable to some studies (for example blinding was not feasible/applicable in some studies), we calculated a percentage index of the ratings against the amount of applicable items for each study. Once not applicable scores were taken into account, articles with scores of 60% or over as strong. To maximize potential learning, bias levels were used to judge the quality of the studies included in the review rather than to exclude studies.

## Synthesis of results

Due to the variance in study designs included in the review, we conducted a narrative descriptive synthesis of the data using 'Guidance on the Conduct of Narrative Synthesis in Systematic Reviews' (Popay et al, 2006) to frame our process. Analysis then took place across the studies.

### Risk of bias across studies

Risk of bias across studies was discussed between *TB* and *ED* to consider selective reporting, publication bias, and the impact of our search strategy on the included studies.

## RESULTS

## Study selection

The database search identified 5935 records and 27 further records were found through the lateral search. After duplicates were removed, 5020 records were assessed for eligibility. After title assessment, 268 abstracts were screened and 93 full texts were retrieved for assessment. Articles not meeting the eligibility criteria were removed. An updated search identified 479 titles, after screening three were included in this review. Thirty-six articles, describing 30 distinct studies, are included in the review (see Figure 1).

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#### Study characteristics

As shown in Table 1, 17 of the 30 included studies were conducted in the United States, six in Canada, three in Sweden, two in Australia, one in France, and one not specified. The majority of studies were quasi-experimental designs (19/30); there were also five randomised controlled trials (RCTs), three cross-sectional studies, one case report, one case control study and one qualitative study. Most studies (28/30) took place in long-term care facilities (20 in nursing homes, 6 in care facilities and 2 in specialised units) and one in psychiatric wards. Of note, only one study recruited people with dementia who were community dwelling. The number of care settings, such as nursing homes, included in individual studies ranged from one to 17, with 15 out of 30 studies involving only one setting.

#### Participant characteristics

All 30 studies included participants living with dementia (average 36, range 1-240 participants). Twenty-two of these provided a mean age for people with dementia (83, range 77-95). Most studies (28/30) stated gender, with more females than males were involved in 25/28 studies. Thirteen out of the 30 studies provided some information on the ethnicity of people of dementia, all of these had a white majority or were entirely white, with other ethnicities included comprising African American, Caribbean Islander, Hispanic, and others. Studies predominantly relied on medical records to determine a dementia diagnosis, although some used measures, with the Mini Mental State Examination (MMSE) used most frequently. Most participants had moderate or advanced dementia and dementia

sub-types, where specified, although predominantly Alzheimer's disease had a mix of types involved.

Eleven studies included staff or caregiver participants (average n=34; range 6-53). All studies stating caregiver gender (10/11) had more females. Caregiver ages ranged from 21-82 (5/11 studies reporting) with an average age of 42 (9/11 studies reporting). Only five studies stated caregiver ethnicity, three of these had a majority white caregiver sample, one had equal white and African American, and one predominantly Caribbean Islanders.

## Risk of bias within studies

Slight differences in reviewer quality ratings were present for 23/36 articles. Inconsistencies were due to oversight, differences in the interpretation of the study, and, most commonly, differences in scoring items as 'unclear' or 'no' when there was limited information. Inconsistencies were discussed between *TB* and *ED* and consensus was reached in all but one case, where EM was referred to as adjudicator. Table 1 shows the quality ratings; 4 articles were rated as strong (S), 22 as moderate (M) and 10 as weak (W). However, some of those rating moderate had very small sample sizes (including four quasi-experimental designs), which are not taken into account in the quality assessment items.

## Risk of bias across studies

Due to the inclusion of negative, weak and inconclusive results in the included studies, the risk of publication bias or selective reporting was thought to be low. The impact of the search strategy and terminology used in articles may have led to only certain studies being identified and included in this review.

## Intervention characteristics

Intervention characteristics are presented in Table 2. The nature of the interventions was varied, covering music, humming, caregiver approaches including communication and interaction style, video-stimulated presence, distraction approaches, slow stroke massage, aromatherapy, abilities focussed approaches, and bathing techniques. Different care activities were examined, with the majority of studies focussing on mixed or general care activities (n=14) or bathing (n=8). Mealtimes (n=4), mouth care (n=2), and medication administration (n=2) were also covered. Intervention duration ranged from a one-off interaction to 6 months. Where specified, most interventions were implemented by usual staff (certified nursing assistants and/or nurses) (n=16), but also by research team members (n=4) and family carers in one study. Many interventions relied on training or asking staff members to adapt their approach (n=14), although five studies conducted retrospective analyses of usual care interactions where there was no intervention. Outcomes were most commonly assessed using direct observation (n=17), with video-recorded observations being used less frequently (n=8), retrospective assessments were used by five studies, one of those being assessed by family carers. A wide range of outcome measures were used, most commonly this was a bespoke tool (n=7), but the Cohen Mansfield Agitation Inventory (n=5) and the Resistiveness-to-Care Scale (n=5) were also used in several studies.

#### Interventions involving music

Seven studies focussed on music in some way, one RCT (Clark, Lipe and Bilbrey, 1998) and six quasi-experimental studies (Thomas, Heitman and Alexander, 1997; Hicks-Moore, 2005; Richeson and Neill, 2004; Loko et al, 2018; Hammer et al, 2010a, Hammer et al, 2010b; Engstrom and Hammer, 2012). The RCT (n=18) was of weak quality and found that playing residents' preferred music during bathing significantly reduced the total number of

observed behaviours and hitting, but that there was a non-significant increase in physical resistance. No effect sizes were reported (Clark, Lipe and Bilbrey, 1998).

The quasi-experimental studies focussed on playing music (relaxing or resident's preference), singing or humming, during either mealtimes, morning care or bathing. Playing individualised music during bathing significantly reduced aggressive behaviours (P=.005), no effect size reported (n=14, M) (Thomas, Heitman and Alexander, 1997). Playing relaxing music during mealtimes decreased overall incidences of behaviours in one study (n=30, M) by half (Hicks-Moore, 2005) and reduced overall agitation by 21% in another study (n=27, W) (Richeson and Neill, 2004). The MUSIC CARE intervention, involving personalised musical sequences leading to relaxation, played during morning care significantly decreased refusals compared to control or a radio condition (n=21, W) (Loko et al, 2018).

Music Therapeutic Caregiving (MTC) where caregivers communicated through singing about other things than the care interaction during morning care significantly reduced resistant behaviours (pull away, grab object, adduction) and significantly increased positively expressed emotions (pleasure, general alertness) for the majority of participants, although some were still resistant (n=10, M) (Hammer et al, 2010<sup>a</sup>, Hammer et al, 2010<sup>b</sup>). One other quasi-experimental study (n=2, M) examined caregivers humming during mealtimes with two residents, results were contradictory, but indicated a slight improvement in refusal behaviours (Engstrom and Hammer, 2012).

### Interaction and communication style

Five studies examined interaction and communication style, one RCT (Williams et al, 2017), three cross-sectional (Belzil and Vezina, 2015, Williams et al, 2009, Herman and Williams, 2009, Williams and Herman, 2011; Christenson et al, 2011) and one case control (Amella,

2002). The CHAT Intervention, a communication intervention to reduce the use of elderspeak (for example, using overly-endearing terms and tones, over-accommodating, repetition, speaking more slowly, and with simpler sentence structures and vocabulary) by nursing staff was tested in an RCT (n=27, M). Resident refusal behaviour was reduced by the intervention, with each percentage point decrease in elderspeak associated with 0.43 percent point decrease in refusals. Refusal behaviour was found to be predicted by elderspeak use (b=0.43, p<.001) and refusal behaviours present at baseline (b=-0.65, p<.001) (Williams et al, 2017).

Three cross-sectional studies conducted retrospective analyses of caregivers' communication styles during care interactions (Belzil and Vezina, 2015 (n=8); Williams et al, 2009, Herman and Williams, 2009, Williams and Herman, 2011 (n=20); Christenson et al, 2011 (n=11)). Cross-sectional studies are useful for identifying associations, but cannot show effectiveness. All three studies were of moderate quality and analysed video-recorded interactions, which focussed on hygienic care and activities of daily living. Results showed moderate associations between negative statements (AR=8.26, p<.001, OR=2.37, Yule's=Q 0.41), and positive (AR=15.09, p<.001, OR=1.96, Yule's Q=0.32) and negative instructions (AR=9.31, p<.001, OR=2.08, Yule's Q=0.35) and refusals (Belzil and Vezina, 2015). Elderspeak created a higher probability of refusals (Bayesian hierarchical model: .55, 95%Crl=.44-.66), as did highly controlling communication (for example, bossy, directive and dominating tones), which was significantly associated with increased refusal behaviours (r=.49, p<.05), (Williams et al, 2009, Herman and Williams, 2009, Williams and Herman, 2011). A significant association was found between clear, concise and feasible commands and higher compliance compared to ambiguous, interrupted and infeasible commands ( $\chi^2$  (1, n=737) =43.13, p<.01) (Christenson et al, 2011). The case control study (n=53, S) focussed on the

breakfast meal and found that residents who refused were more likely to be bothered, inflexible, and agitated than residents accepting assistance. Refusals were moderately correlated with food consumed (r=.49 -.68, p<.02) (Amella, 2002).

#### **Caregiver approach**

There were five different interventions focussed on caregiver approaches. The six studies investigating these approaches used quasi-experimental (n=3) (Mickus et al, 2002; Karlin et al, 2013; Jablonski et al, 2012), RCT (n=1) (Jablonski et al, 2018), case report (n=1) (Simard, 2017) and qualitative (n=1) (Hallberg et al, 1995) designs. One quasi-experimental study (n=23, M) examining PRIDE, an intervention focussed on caregivers providing privacy, reassurance, information, distraction and evaluation found that it significantly reduced anxiety (p=.016) and irritability (p=.016) and frequency of behaviours was reduced. No effect sizes reported (Mickus et al, 2002). Another quasi-experimental study (n=64, W) examining STAR-VA, a multi-component psychosocial intervention, aimed at reducing all dementia-related behaviours, found that refusals of care significantly decreased in frequency (Cohen's d = 1.5; p=.002) and severity (Cohen's d = 1.0; p=.003) over a period of 6-months (Karlin et al, 2013), however the quality score for this study was weak.

The MOUTh Intervention aims to improve oral care through best oral hygiene practices and threat reduction strategies. The pilot quasi-experimental study (n=7, M) found reduced refusal behaviours, but the change was not statistically significantly. Of note, oral hygiene improved significantly (Jablonski et al, 2011). The MOUTh Intervention RCT (n=100, S) found the intervention had no effect on the frequency of refusals, but there was a non-significant decrease in intensity of behaviours (Cohen's d = -0.16). However, those receiving the intervention were more likely to verbally or non-verbally agree to have assistance with

mouth care before the interaction and to have mouth care completed (Cohen's d > 0.3) (Jablonski et al, 2018). During the RCT, researchers noted that the MOUTh intervention developed into a relationship-centred intervention where the mouth care practitioners' approaches focussed on pre-empting and addressing refusal behaviours through using distraction, rescue, bridging and hand over hand strategies (Jablonski-Jaudon et al, 2016).

Through a qualitative study of usual care (n=22, M), Hallberg found that when the nurse and patient worked in pace and mutuality with each other, co-operation and interaction was present. When out of pace with each other and working unilaterally, co-operation was usually task oriented and refusal behaviours were present (Hallberg et al, 1995). A case report (n=1, W) described how Namaste Care has potential to reduce refusal behaviours in late-stage dementia by creating a calm environment and using a loving touch approach (Simard, 2017). Since conducting the search for this systematic review, a feasibility, parallel, two-arm, multicentre cluster controlled randomised trial (n=32) was conducted to assess the feasibility of a full RCT for Namaste Care. The feasibility trial did not assess refusals; however, staff and informal carers reported that with Namaste Care the resident participants were more calm (Froggatt et al, 2020). Although qualitative and case report studies cannot provide evidence for effectiveness, we can take from them ideas for possible successful relational approaches that may be tested in future studies.

### **Bathing techniques**

Three studies focussed on bathing techniques (Hoeffer et al, 2006; Sloane, Hoeffer and Sombootanont, 2006; Sloane et al, 2004; Gozalo et al, 2014; Dunn, Thiru-Chelvam and Beck, 2002). Two RCTs tested the Bathing without a Battle intervention (training in person centred showering and towel bathing). One (n=69, S) featured direct training of certified nursing

assistants, which reduced aggression by 53% in the person centred shower group (P<.001) and 60% in the towel bath group (p<.001) (no effect sizes reported) (Sloane et al, 2004; Sloane, Hoeffer and Sombootanont, 2006). There were non-significant effects (ranging between -0.44 and -0.69) for the reduction of hassles for example the resident complaining or yelling (Hoeffer et al, 2006). The other (n=240, W) employed a train the trainer model, which also had a significant reduction in instances of physically or verbally aggressive or agitated behaviour (p=.004), a reduction of 18.6 percent (Gozalo et al, 2014). The third bathing techniques study (n=15, M) examined the usual tub bath compared to the thermal bath (moist warm washcloths used at bedside with non-rinse skin cleanser) via a quasiexperimental design. The sum of all behaviours was significantly lower (p<.01) in the thermal bath condition (731), which elicited half of the behaviours of the usual tub bath condition (1468) (Dunn, Thiru-Chelvam and Beck, 2002).

#### **Abilities focussed approaches**

Three quasi-experimental studies focused on maximising the abilities of the person with dementia as a way to reduce refusal behaviours (Rogers et al, 1999; Sidani, Streiner and LeClerc, 2011; Wells et al, 2002). Two of these trained caregivers with educational sessions and focussed on morning care. One (n=65, M) found no statistically significant change in levels of agitation or resistance to care but did find an increase in relaxation and calmness (effect sizes of low to moderate) (Sidani, Streiner and LeClerc, 2011), the other (n=40, M) found a significant decrease (t=-2.12, df = 38, p=.041) in levels of agitation (Wells et al, 2002). The third abilities focussed study (n=84, M) used a research therapist to deliver skill elicitation and habit training to people with dementia during dressing to reduce what they termed 'disruptive behaviour'. Behaviours during dressing decreased significantly during the

skill elicitation training period (t=-2.74, p=.01), this reduction increased slightly during the habit training period, but not to pre-intervention level (Rogers et al, 1999).

#### **Distraction approaches**

One quasi-experimental study (n=4, W) used positive images (a baby, puppies) that residents had responded to previously to see if they could be used in morning care to reduce refusal behaviours. All four residents displayed fewer behaviours with the positive images than the control (mean difference of Agitated Behavior Scale scores before 6.75 and after the intervention 2.22) and residents were slightly more engaged (Chou et al, 2016). Sample size was small and the quality score for this study was weak. In another quasi-experimental study (n=31, M), trained staff delivered a natural elements approach with sounds, pictures and foods, which were talked about with residents during showers. The natural elements approach significantly decreased agitation (p<.004) during showers, however the decrease in physical aggression did not reach significance (Whall et al, 1997). No effect sizes were reported.

### Aromatherapy

Two studies focussed on aromatherapy, one (n=36, W) using a blend of lavender, sweet marjoram, patchouli, and vetiver applied in cream (Bowles et al, 2002) and one (n=13, M) using separate tea-tree, sweet orange, lavender vera, and no aroma (as a control) conditions on cotton wool attached to the person (Gray and Clair, 2002). Both studies found no statistical significant differences in refusal behaviour when aromas were used. Of note, a significant increase in refusal behaviour occurred in one of the intervention groups with the mixed-aroma cream (p=.0026) (Bowles et al, 2002).

#### Slow stroke massage

The only study (n=9, M) using family carers to implement the intervention focussed on slow stroke massage over five days (Rowe and Alfred, 1999). Slow stroke massage did not significantly reduce refusal behaviours; however, mean scores showed a reduced trend during the intervention phase.

### Video simulated presence

One study (n=1, M) examined the principle of video-simulated presence of a loved one asking the person with dementia to comply with staff requests at meal times and with medication administration (O'Conner et al, 2011). This study had only one participant, however, there was a significant improvement in their refusal behaviour when using this intervention (p=.002), which ceased once the intervention was withdrawn.

#### DISCUSSION

All music interventions (except humming) and different models of bathing reduced instances of refusal behaviours. Music studies included one RCT (Clark, Lipe and Bilbrey, 1998 (n=18, W)) and five quasi-experimental studies (Thomas, Heitman and Alexander, 1997 (n=14 M); Hicks-Moore, 2005 (n=30 M); Richeson and Neill, 2004 (n=27 W); Loko et al, 2018 (n=21 W); Hammer et al, 2010a; Hammer et al, 2010b, (n=10 M)). Of note, playing recorded music (for example via a compact disc during care activities) or caregiver communication through singing and not inherently active approaches for people with dementia such as playing instruments worked to reduce refusal behaviours. These interventions are cheap and time efficient to implement, making them simple for anyone to adopt. Bathing techniques included different modes of bathing such as the towel bath, person centred

showering or thermal bath as opposed to usual tub bathing. Bathing technique studies were two RCTs (Hoeffer et al, 2006; Sloane, Hoeffer and Sombootanont, 2006; Sloane et al, 2004 (n=69 S); Gozalo et al, 2014 (n=240 W)) and one quasi-experimental study (Dunn, Thiru-Chelvam and Beck, 2002 (n=15, M)). Interaction and communication style strategies had encouraging evidence from cross-sectional studies, highlighting styles associated with refusal behaviours. Communication styles such as elderspeak and controlling or negative communication were associated with refusal behaviours (Williams et al, 2009; Herman and Williams, 2009; Williams and Herman, 2011 (n=20 M); Belzil and Vezina, 2015 (n=8 M)). Reducing elderspeak, as demonstrated by the CHAT Intervention RCT is likely to reduce refusal behaviours (Williams et al, 2017 (n=27 M)).

Abilities focussed approaches in quasi-experimental studies (all of moderate quality) had mixed effects, reducing agitation in one (Wells et al, 2002 (n=40 M)) and disruptive behaviour in another (Rogers et al, 1999 (n=84 M)), but making no statistically significant change to behaviours in a third study (Sidani, Steiner and LeClerc, 2011 (n=65 M)). This third study provided less training to staff and less intervention time, which are likely to be important factors. Studies that focussed on the caregiver approach had mixed results for reducing refusal behaviours. In quasi-experimental studies, psychosocial interventions such as STAR-VA (Karlin et al, 2013 (n=64 W)) or PRIDE (Mickus et al, 2002 (n=23 M)) reduced the frequency of refusal behaviours. The RCT testing the MOUTh Intervention, based on relationships and threat reduction strategies did not reduce refusal behaviours (Jablonksi et al, 2018 (n=100 S)). There was weak indicative evidence in a case report for Namaste Care (Simard, 2017 (n=1 W)) and video-simulated presence of a loved one in a quasi-experimental study with a sample of n=1 (O'Conner et al, 2011 (n=1 M)) as potential interventions to reduce refusal behaviours. Quasi-experimental studies of distraction-based

interventions such as using natural elements reduced agitation (Whall et al, 1997 (n=31, M)), and the use of positive images, although only weak limited evidence available, could be promising (Chou et al, 2016 (n=4, W)). There was no evidence for aromatherapy interventions to reduce refusal behaviours in dementia (Gray and Clair, 2002 (n=13 M); Bowles et al, 2002 (n=36 W)).

Our review adds to previous knowledge (Konno et al, 2014) by examining the literature beyond the setting of nursing homes and including multiple different methodologies. This approach has enabled us to provide a comprehensive overview of this research area identifying promising strategies found by different methodologies such as, retrospective analyses of usual care, which illuminated the communication styles which are associated with refusal behaviours. Additionally, our approach allowed us to identify research gaps such as the settings where investigations into interventions and strategies in relation to refusals of assistance with personal care are absent, such as hospitals where refusals of care have been identified as pervasive (Harwood et al, 2018; Featherstone, Northcott and Bridges, 2019). Harwood et al's study of conversation analysis in hospital wards, excluded from this review due to not focussing solely on personal care interactions, but communication interactions more generally, adds weight to our findings about the importance of communication style. They found that making requests clear and simple, trying to make the task sound easier, and speaking with authority all worked to reduce refusals of requests (Harwood et al, 2018).

### Strengths and Limitations

This review used strict inclusion criteria and standardised processes for assessing studies and extracting data. We included studies using different methodologies to maximise our

learning. However, as the studies used various outcome measures and types of intervention, and focussed on different personal care activities this created difficulties in synthesising data and comparing results. Terms such as 'agitation', 'hassles', 'challenging behaviour', 'aggression' or 'disruptive behaviour' and not refusals/resistance were used in some studies. There is the possibility that this could mean that people with dementia in these studies had global agitation or disruptive behaviours, which continued into the care interaction and that behaviours did not appear as a result of the personal care interaction. However, when assessing articles for inclusion we specifically only included articles focussed on outcomes during, or relating directly to, refusals of personal care in dementia, therefore those studies included are still able to inform us about behaviours during care interactions. Some intervention studies have a wider focus of reducing dementia-related behaviours such as agitation or aggression, or anti-psychotic medication use, for example those examining massage and touch therapy (such as, Suzuki et al, 2010; Watt et al, 2019). These types of studies could have findings which may be useful to relax people with dementia and therefore indirectly reduce refusals of care.

We conducted quality assessments on all articles; however, as this review was exploratory in nature, we did not exclude articles with low quality. Therefore, some of the findings discussed in this review are of a weak quality. Additionally, some studies had small sample sizes, some of these were appropriate as for a case report. However, quasi-experimental studies with small sample sizes may reflect the nature of the evidence base, funding availability, and research question as being difficult to address, for example, focussing in on intimate personal care interactions. Multiple studies did not report effect sizes, further indicating limitations in the type and scope of evidence available in this research area. The reporting quality of strategies and interventions in the articles was generally poor.

Considering that the majority of strategies and interventions to reduce or manage refusals were complex interventions, poor reporting has important consequences for assessing the applicability and replicability of the results.

#### Risk of bias across studies

Studies in this review were predominantly set in long-term care settings, so findings may not be applicable to other settings such as family homes or hospitals. Due to the complex nature of refusals of care, instances were framed in many different ways, for example, some studies classed refusals as agitation or aggression during care, disruptive behaviours, or as refusals/resistance. Due to this diversity in describing refusals and the multitude of ways that it can manifest (for example, moving away, clamping jaw, verbal aggression, hitting, nipping), along with the different personal care activities and interventions there is a possibility that our search did not identify all studies covering this issue.

### CONCLUSIONS

Many interventions and strategies have been identified to reduce refusal behaviours during personal care in dementia. There is no evidence that refusal behaviours can be eliminated, but some interventions and strategies can be successful in reducing refusals. Playing music, offering different bathing options, reducing elderspeak and negative communications, and some psychosocial interventions can reduce refusal behaviours in dementia. There is no evidence that aromatherapy or slow stroke massage reduces refusals. Evidence in this research area is often weak and small scale. Further research should focus on obtaining good quality evidence for promising interventions, such as distraction techniques and

Namaste Care. Testing evidenced interventions and promising strategies in hospital and family settings, including with home-care workers would be beneficial.

## **FUNDING SOURCES**

This review was conducted at the University of East Anglia following the receipt of funding from the Alzheimer's Society (AS-JF-17-002) for author TB. EM and AK are supported by the National Institute for Health Research (NIHR) Applied Research Collaboration East of England (ARC EoE) programme. The views expressed are those of the authors, and not necessarily those of the Alzheimer's Society, University of East Anglia, NIHR, NHS or Department of Health and Social Care.

## **CONFLICT OF INTERESTS**

None

Study Reference	Location	Study Design	Study Setting/s	Inclusion Criteria	Exclusion Criteria	Sample size/ participants	Mean age (range)	Quality score
Music Interv	ventions							
Clark 1998	United States	RCT	1 Nursing home	Dementia diagnosis, history of aggressive behaviours during care	Uncorrected hearing impairment, absence of informant family member	18 Residents	82 (52-95)	Weak
Engstrom 2012	Sweden	Quasi- experimental	1 Nursing Home	Severe dementia, assisted with feeding, living at the nursing home for more than 20 weeks	Not specified	2 Residents	Not specified	Moderate
Hammer 2010 <sup>a</sup> Hammer 2010 <sup>b</sup>	Sweden	Quasi- experimental	2 Nursing homes	Dementia diagnosis	Not specified	10 Residents 6 Caregivers	81 (66-92) - (31-54)	Moderate Moderate
Hicks- Moore 2005	Canada	Quasi- experimental	1 Specialised care unit	Residing on the unit, diagnoses of irreversible dementia, Alzheimer's disease, or severe cognitive impairment	Not eating in the common dining room	30 Residents	82 (70- 101)	Moderate
Loko 2018	France	Quasi- experimental	1 Residential care facility	Alzheimer's disease or other diseases responsible for cognitive disorders, receiving assistance for morning toileting	End of life	21 Residents	87 -	Weak
Richeson 2004	United States	Quasi- experimental	1 Nursing home	Dementia diagnosis, eats evening meal in the dining room	Not specified	27 Residents	87 (67-94)	Weak
Thomas 1997	United States	Quasi- experimental	1 Nursing home	Dementia of moderate stage, 3-months in the facility, resistant to bathing, interested in music	Not specified	14 Residents	- (69-86)	Moderate

## Table 1 Study Characteristics

Study Reference	Location	Study Design	Study Setting/s	Inclusion Criteria	Exclusion Criteria	Sample size/ participants	Mean age (range)	Quality score
Interaction a	nd Commu	nication Style						
Amella 2002	Canada	Case control	1 Nursing home	Late-stage dementia	Tube fed, or augmented or restricted diet	53 Dyads (residents and caregivers)	80 - 40 -	Strong
Belzil 2015	Canada	Cross- sectional	1 Nursing home	In the nursing home for at least three months, dementia diagnosis, exhibiting resistance to care behaviours during care in the last fortnight	Not specified	8 Residents 43 Caregivers	81 (76-86)	Moderate
Christenson 2011	United States	Cross- sectional	2 Nursing homes 1 Special care unit	65 years or older, diagnosis of dementia	Not specified	11 Residents 11 Caregivers	Not specified Not specified	Moderate
Herman 2009 Williams 2011 Williams 2009	United States	Cross- sectional	3 Dementia care facilities	Older adults with dementia	Not specified	20 Residents 52 Nursing staff	83 (69-97) 35 (21-54)	Moderate Moderate Moderate
Williams 2017	United States	RCT	13 Nursing homes	Diagnosis of AD or other dementia, long stay resident status, staff report of resistance to care at least 10% of the time, ability to hear, surrogate decision maker	Huntington' disease, alcohol-related dementias, schizophrenia, manic- depressive disorder, deafness, mental issues, hospice care	27 Residents 29 Staff	88 (72- 104) 37 (21-67)	Moderate
Caregiver Ap	proach				, , , , , , , , , , , , , , , , , , , ,			
Hallberg 1995	Sweden	Qualitative	2 Psycho- geriatric unit wards	Dementia	Not specified	22 Patients 29 Nurses	81 - 34 -	Moderate

Study Reference	Location	Study Design	Study Setting/s	Inclusion Criteria	Exclusion Criteria	Sample size/ participants	Mean age (range)	Quality score
Caregiver Ap	oproach Cor	ntinued						
Jablonski 2011	United States	Quasi- experimental	1 Nursing home	Dementia or AD diagnosis of moderate or severe stage, age 65 or older, at least 2 adjacent teeth or using a removable denture, consistent care resistant behaviours, moderate dependence on others for care	Not specified	7 Residents	82 -	Moderate
Jablonski 2018 Jablonski 2016	United States	RCT	9 Nursing homes	Age 55 or older, dentate with least 2 adjacent teeth or using a complete denture in at least one arch, any type of dementia, able to grasp a toothbrush, exhibiting care resistant behaviours	Dysphagia	100 Residents	82 -	Strong Weak
Karlin 2013	United States	Quasi- experimental	17 Veterans Affairs Nursing Homes	Real-life veterans with challenging dementia- related behaviours	Unstable psychosis	64 Residents 45 Staff	Not specified Not specified	Weak
Mickus 2002	United States	Quasi- experimental	1 Nursing home	Behaviours during bathing	Not specified	23 Residents	77 (23- 100)	Moderate
Simard 2017	Australia	Case report	1 Nursing home	Dementia diagnosis, advanced stage	Not specified	1 Resident	Not specified	Weak
Bathing Tecl Dunn 2002	hniques Canada	Quasi- experimental	1 Continuing care centre	Dementia diagnosis	Not specified	15 Residents	81 (67-93)	Moderate

Study Reference	Location	Study Design	Study Setting/s	Inclusion Criteria	Exclusion Criteria	Sample size/ participants	Mean age (range)	Quality score
Bathing Tecl	•							
Gozalo 2014	United States	RCT	6 Nursing homes	A Cognitive Performance Scale score of 2 or above, been a nursing home resident for 90 days or longer	Feeding tube, delirium, hospice care, unconscious, comatose, Huntington's disease, acquired immunodeficiency syndrome, alcohol- related dementia, or psychotic disorder	240 Residents	85 -	Weak
Hoeffer 2006 Sloane 2006 Sloane 2004	United States	RCT	15 Nursing homes	Aged 55 and older; assisted in bathing, AD or a related dementia, moderate or severe cognitive impairment, agitation or aggression during bathing, able to be showered.	Dementia due to alcoholism, Huntington disease, or acquired immune deficiency syndrome, psychosis as a primary diagnosis, to be discharged or die within 6 months, not speak English.	69 Residents 37 Nursing assistants	86 - 38 -	Strong Weak Strong
<b>Abilities Foc</b>	ussed Appro	oaches			·			
Rogers 1999	United States	Quasi- experimental	5 Nursing homes	Dementia diagnosis, expecting to remain in the facility for at least 3 months, dressing disability	Hospice patients, life expectancy of less than 6 months, dressing disability not attributable to dementia, history of schizophrenia or alcoholism, non- English speaking	84 Residents	82 (64-97)	Moderate

Study Reference	Location	Study Design	Study Setting/s	Inclusion Criteria	Exclusion Criteria	Sample size/ participants	Mean age (range)	Quality score
Abilities Foc	ussed Appro	oaches Continue	ed					
Sidani 2011	United States	Quasi- experimental	8 Long-term care facilities	Dementia diagnosis associated with Alzheimer's disease, Lewy bodies or vascular disease or mixed dementia, had a substitute decision-maker to provide proxy consent	Cerebrovascular accident, Parkinson's disease, developmental delay, major depression, Huntington's chorea and acquired brain injury	65 Residents	83 (58- 100)	Moderate
Wells 2002	Canada	Quasi- experimental	4 Cognitive support units	Dementia diagnosis, moderate or severe level of cognitive impairment, length of stay on the unit of at least 4 weeks	Not specified	40 Residents 44 Caregivers	89 - 45 -	Moderate
Distraction A								
Chou 2016	Not specified	Quasi- experimental	1 Nursing Home	Dementia and agitated behaviours	Bipolar disorder or schizophrenia	4 Residents	95 -	Weak
Whall 1997	United States	Quasi- experimental	5 Nursing homes	Recently reconfirmed AD or a mixture of AD with multi- infarct dementia and congruent symptoms, agitated aggressive behaviour during shower, scores of five or less on the Mini Mental Status Exam, psychotropic drugs maintained	Acute health condition	31 Residents 25 Nurse aides	Not specified Not specified	Moderate
Aromathera							(	
Bowles 2002	Canada	Quasi- experimental	1 Residential care facility	Severe or third stage dementia	Allergy to cream	36 Residents	- (70-92)	Weak

Study Reference	Location	Study Design	Study Setting/s	Inclusion Criteria	Exclusion Criteria	Sample size/ participants	Mean age (range)	Quality score
Aromathera	py Continue	ed						
Gray 2002	United States	Quasi- experimental	2 Residential care facilities	Dementia, difficult-to- manage behaviours, including resistance to receiving medications, ability to perceive aromas	Not specified	13 Residents	Not specified	Moderate
Slow Stroke	Massage							
Rowe 1999	United States	Quasi- experimental	Community dwelling	Diagnosed with probable AD, speak English	Not specified	9 Dyads (PwD & family carer)	77 (68-90)	Moderate
Video-simula	ated Presen	се						
O'Connor 2011	Australia	Quasi- experimental	1 Nursing home	Diagnosis of dementia, able to engage with video, recognise family member, and comprehend instructions, frequent resistance to care with basic care tasks	Not specified	1 Resident	83 (n=1)	Moderate

RCT – Randomised Controlled Trial, PwD – People with Dementia, AD – Alzheimer's Disease

Reference	Intervention; Delivered	Duration of	Personal	Observation;	Relevant Findings
	by	intervention	care activity	Outcome measure/s	
Music Interve	ntions				
Clark 1998	Participants' preferred music played during bathing; Not specified	10 bathing episodes for each participant over 2 weeks	Bathing - including partial bath or shower	Direct observation by 4 researchers; Bespoke check sheet of target behaviours	Total number of observed behaviours and hitting significantly reduced. Other behaviours reduced but not significantly. Some behaviours increased but not significantly
Engstrom 2012	Humming; Caregiver	2 baseline, 2 intervention, 1 post intervention	Eating	Video-recorded observations; EdFED 6 behaviours	Results contradictory but indicate slight improvement in refusal behaviours. Humming during mealtimes might enhance eating and feeding
Hicks-Moore 2005	Music – relaxing music played during the evening meal; Not specified	2 x 1-week interventions during evening meal	Mealtimes	Direct observation by a recorder; Modified CMAI	69 behaviours reduced to 32 in the first intervention period and 51 behaviours to 24 in the second intervention period
Hammer 2010 <sup>ª</sup> Hammer 2010 <sup>b</sup>	Music Therapeutic Caregiving (MTC) - Communicating through singing; Trained caregivers	40 videoed observations - 10 hours analysed	Morning care - dressing upper body	Video-recorded observations by researcher; RTC, OERS and QCA	Resistant behaviours (pull away, grab object, adduction) significantly reduced with MTC and positively expressed emotions (pleasure, general alertness) significantly increased
Loko 2018	MUSIC CARE - personalised musical sequences leading to relaxation; Care worker	3 sessions per resident: radio, no intervention, MUSIC CARE	Morning toileting and washing	Resident and care worker post- interaction reports on a scale 0-10	Significant decrease in refusal of care score in the MUSIC CARE situation compared to control (P<0.001), not found in the radio situation
Richeson 2004	Music – relaxing CD played during evening meal; Not specified	4 hours over 4 days	Dinnertime 5-6pm	Direct observations by researchers; Modified CMAI	Decreases were found in overall agitation -21%, physically non-aggressive behaviours -17.9%, general restlessness -56%, verbally aggressive behaviours - 6%, cursing -25%. No changes in hiding or hoarding
Thomas 1997	Individualised Music played; CNAs	Three music baths - music prior and during bathing	Bathing	Trained certified nursing assistants; Modified CMAI	Aggressive behaviour significantly reduced (p=.46, p=.005, p=.014 for subsequent baths) during the intervention, but not hiding, physically nonaggressive behaviour and verbally agitation

# Table 2 Interventions and strategies to reduce refusals of care

Amella 2002	Retrospective analysis of usual care - Quality of interaction; CNAs	One off - observations of breakfast meal	Eating; breakfast meal	Direct observation by research assistant; IBM and IBM-M	Resident who refused had significantly lower scores on bothered vs cool (P= .001), agitated vs calm (p= .001), resistant vs cooperative (p= .000), inflexible vs flexible (p= .043)
Belzil 2015	Retrospective analysis of usual care - Positive and negative instructions; Caregivers	Video-recorded observations of hygienic care - 30 per resident (240)	Hygienic care	Video-recorded observations; Physical and verbal behaviours	Negative statements and instructions (and positive instructions if the recipients language is severely deteriorated) could lead to refusals regardless of recipients prior behaviour (p<0.0001)
Christenson 2011	Retrospective analysis of usual care communication and commands used; Caregivers	Video recorded observations 2 or 3 interaction sessions	Any activities of daily living	Video recorded observations; command types/compliance - coded by researchers	Clear, concise and feasible commands lead to higher compliance when compared to ambiguous, interrupted and infeasible commands. Commands stated directly, repeated commands, produce better compliance
Williams 2009 Herman 2009 Williams 2011	Retrospective analysis of usual care - communication and elderspeak; Nursing staff	80 interactions video-recorded - mean length 4.58 minutes (range .5-10)	Bathing, eating or oral care, dressing, and other ADL activities	Video-recorded observations; RTC Coded to elderspeak, silence and normal adult speech	A significant association between both staff communication type (p=<.001) and highly controlling communication (p<.05) and subsequent resident refusals. Refusal behaviours of push away, no/negative, and scream/yell were significantly more likely to co-occur with elderspeak
Williams 2017	CHAT training intervention- reduced elderspeak and communication; Nursing staff	3 CHAT training sessions x1 a week over a 3- week period.	Morning care	Video recorded observations 6 days (3 time points); RTC & elderspeak communication	Resident refusal behaviour was significantly reduced post intervention. A 1% point decrease in elderspeak was associated with a 0.43% points decrease in refusals
Caregiver App					
Hallberg 1995	Analysis of usual care observations – patient actions, environmental conditions, nurse actions; Ward staff	No intervention - observations lasted for 1 hour 107 observations over 18 months	Morning care	Observation notes from 1 researcher observer	Nurse-patient cooperation was found to be better when acting in mutuality or unilaterality and in pace with each other.
Jablonski 2011	MOUTh intervention - best oral hygiene practices, threat	Mouthcare provided twice daily for two	Mouth care	Direct observations by researchers; Modified RTC-r	Non-significant reduction in mean refusal behaviours from baseline to intervention (p=.06). Oral health improved significantly (p<.001)

	reduction strategies; Researchers	weeks			
Jablonski 2018 Jablonski- Jaudon 2016	MOUTh Intervention - Threat reduction strategies, relationship- centred; Mouthcare practitioners	Mouthcare was provided to participants twice daily for 3 weeks	Mouth care	Direct observations by care resistant behaviour raters; RTC-r	No reduction in the frequency of refusal behaviours. Non-significant reduction in intensity of refusal behaviours. Assent to and completion of mouth care significantly improved. Relationship-based interventional factors emerged
Karlin 2013	STAR-VA psychosocial intervention; mental health workers trained then cascaded to Nursing Home staff	2.5-day training, weekly calls over 6-months. STAR- VA intervention average 46-days	General staff approach intervention	Mental health worker and staff partner ratings; STAR-VA ABC Card, RMBPC	Frequency (p=.002) and severity (p=.003) of refusing care significantly decreased during the intervention
Mickus 2002	PRIDE (Training: Privacy, Reassurance, Information, Distraction, Evaluation); Nursing assistants	30 minutes training seminar 1 intervention bath observed	Bathing	Direct observation by researcher; NPI - 5 subsets agitation, anxiety, irritability, apathy, disinhibition	42% had at least 3 behaviours pre-intervention compared to 17% post-intervention. All 5 subgroup behaviours under consideration improved after the intervention- anxiety (0.016) and irritability (0.016) significantly reduced
Simard 2017	Namaste Care - creating a calm environment, a loving touch approach; Nursing aides	A few months	Bathing	Informal observation and hearsay from staff; none	Namaste care enabled this resident (n=1) to become comfortable with being touched and resisting care ceased
<b>Bathing Tech</b>	niques				
Dunn 2002	Tub bath and Thermal Bath; Staff attendants	4 sessions of tub bath and thermal bath over an 8 week period	Bathing	Direct observation by observers; Bespoke checklist informed by CMAI and RAS	Sum of all 14 behaviours was significantly (p<.01) smaller in the Thermal Bath than the Tub Bath condition
Gozalo 2014	Bathing Without A Battle- Train the trainer. Person centred showering and towel bathing; CNAs and Registered Nurses	2-days training trainers –up to 2 months to train all staff; 2 bathing episodes per participant	Bathing – including showering and towel bath	Direct observations by non-participant data collector; Modified CAREBA	Significant reductions in 'any physically or verbally aggressive or agitated behaviour' 'any verbally aggressive or agitated behaviour' and 'calling for help or protesting'. Non-significant changes in other behaviours such as, grabbing caregiver, hitting, kicking, biting, throwing objects, spitting, yelling
Hoeffer	Bathing without a Battle	6 weeks of each	Bathing/	Video-recorded	Aggression declined 53% in the person-centred

2006 Sloane 2006 Sloane 2004	- Training in Person centred showering and towel bathing; CNAs	intervention, Training 2-days a week for 4 weeks	showering	observations; CAREBA and Hassles During Bathing Scale	shower group (p<.001) and 60% in the towel bath group (p<.001) Non-significant effect sizes for hassles ranged between -0.44 and -0.69
Abilities Focus	ssed Approaches				
Rogers 1999	Skill Elicitation and Habit Training - Skill training for residents; Research therapist	5-days Skill elicitation, 15- days habit training	Dressing	Direct observations by researchers; Computer assisted behaviour recording	Compared to baseline, the rate of behaviours per minute decreased significantly in skill Elicitation (p=.01), increasing slightly during habit training
Sidani 2011	Abilities-focused approach – education Programme for staff; Nursing staff	one 1.5 to 2-hour educational session – 2-days of observations	Morning care	Direct observations by researchers; PAS and Refined ADL Assessment	No statistically significant changes in levels of agitation from pre-test and post-test. Relaxation and calmness significantly increased- effect sizes of low- moderate. Conversation with residents increased
Wells 2002	Abilities-focused approach - enablement education; Caregivers	5 x 20-30 minute sessions & top up sessions over 6 months	Morning care	Direct observations by research assistant; PAS and MIBM	Residents in the experimental group demonstrated a statistically significant decrease in their level of agitation compared with control group residents (P= .041)
Distraction Ap	oproaches				
Chou 2016	Positive images (photos of a baby or puppies); CNAs	Two resistance to care instances one control and one experimental	Dressing and toileting activities	Direct observation and Certified Nursing Assistant ratings; ABS, OME	Agitation decreased for each resident after the intervention and all residents (n=4) were either attentive or slightly attentive during intervention
Whall 1997	Natural elements – sounds, foods, bright pictures; Trained nurse aides	3 x 1-hour training sessions. 2 shower baths 1- week apart	Shower bath	Direct observation by research assistants; Modified CMAI	Agitation decreased significantly in the treatment group as compared to the usual care group
Aromatherap	y				
Bowles 2002	Essential oils and touch; Nursing staff	Essential oils for 4 weeks (28 days x 5 a day)	Nursing care procedures	Nursing staff recordings; Refusal behaviour recorded at shift end	In one participant group refusal behaviours did not change and in the other they increased (p=0.0026). Four aroma conditions: lavender, sweet marjoram, patchouli, and vetiver oil blend
Gray 2002	Aromatherapy; Not specified	4 conditions x 4 - a total of 16	Medication Administrati	Video-recorded observations;	All results showed no statistically significant differences in frequencies of resistive behaviours

		medication administrations	on	Resistive behaviours	across the four aroma conditions (tea-tree, sweet orange, lavender vera; no aroma (control)
Slow Stroke	Massage				
Rowe 1999	Slow stroke massage; Training for family caregivers	5 days of slow stroke massage	General behaviour including resistance	Family caregiver rating; BSRS, ABRSSG	There was no significant difference in resistance to care due to slow stroke massage - although mean scores showed a trend of reduction during the intervention phase
Video-simula	ted Presence (VSP)				
O'Connor 2011	Video Simulated Presence of a family member encouraging resident; Researcher	Individual 30-60 second videos, 12 data points over 14 days	Feeding, medication administratio n	Direct observations by researchers; Bespoke tool based on the PRS	Mean refusal behaviours significantly reduced (p=.002) and more consistent behaviour was present. Post-intervention significant increase in refusal behaviours (p=.003)

\*Statistically significant p<0.05; CNA: Certified Nursing Assistant; CAREBA; CMAI: Cohen Mansfield Agitation Inventory; OME: Observation Measurement Tool; ABS: Agitated Behaviour Scale; RTC: Resistiveness-to-care Scale; RTC-r: Modified Resistiveness-to-care Scale; BSRS: Brief Behavior Symptom Rating Scale; ABRSSG: Agitated Behavior Rating Scale Scoring Guide; PRS: Positive Response Schedule for Severe Dementia; RMBPC: The Revised Memory and Behavior Problems Checklist; IBM: Interaction Behavior Measure; IBM-M: Interaction Behavior Measure – Modified; EdFED: Edinburgh Feeding Evaluation; PAS: The Pittsburgh Agitation Scale; MIBM: The Modified Interaction Behaviour Measure; RAS: Ryden Aggression Scale; NPI: Neuropsychiatric Inventory; OERS: The Observed Emotion Rating Scale; QCA: Qualitative Content Analysis; CAREBA: Care Recipient Behavior Assessment: ADL: Activities of Daily Living; vs: versus Refusals of personal care in dementia: Systematic Review

## References

Alzheimer's Association (2019) Alzheimer's Disease Facts and Figures 2019, Chicago, 1-88.

Alzheimer's Disease International (2015) World Alzheimer Report 2015 The Global Impact of Dementia An analysis of prevalence, incidence, cost and trends, London.

Alzheimer's Society (2007) Home from home: A report highlighting opportunities for improving standards of dementia care in care homes. Alzheimer's Society, London, 1-82.

Amella, EJ. (2002) Resistance At Mealtimes for Persons with Dementia, *The Journal of Nutrition Health & Aging*, 6(2), 117-122.

Ayalon, L., Gum, A.M., Feliciano, L. and Arean, P.A. (2006) Effectiveness of nonpharmacological interventions for the management of neuropsychiatric symptoms in patients with dementia: a systematic review. Archives of Internal Medicine, 166(20, 2182-2188.

Backhouse, T., Camino, J. & Mioshi, E. (2018<sup>a</sup>) What Do We Know About Behavioral Crises in Dementia? A Systematic Review, Journal of Alzheimer's Disease, 62, 99-113 DOI 10.3233/JAD-170679.

Backhouse, T., Dudzinski, E., Killett, A. and Mioshi, E. (2019) *Strategies* and interventions to reduce or manage refusals in personal care in dementia: a systematic review. *PROSPERO 2019* CRD42019137465 Available from:

http://www.crd.york.ac.uk/PROSPERO/display\_record.php?ID=CRD42019137465

Backhouse, T., Killett, A., Penhale, B., Burns, D. & Gray, R. (2013). Behavioural and psychological symptoms of dementia and their management in care homes within the East of England: a postal survey. Aging & Mental Health, 18(2), 187-193.

Backhouse, T. Penhale, B, Gray R. and Killett, A. (2018<sup>b</sup>) Questionable practices and good intentions: coping with risk and impact from dementia related behaviours in care homes, Ageing & Society

Belzil, G. and Vezina, J. (2015) Impact of caregivers' behaviors on resistiveness to care and collaboration in persons with dementia in the context of hygienic care: an interactional perspective, *International Psychogeriatrics*, 27(11), 1861-1873.

Bird, M., Jones, R. H., Korten, A. and Smithers, H. (2007) A controlled trial of a predominantly psychosocial approach to BPSD: treating causality, International Psychogeriatrics, 19(5).

Bowles, EJ., Griffiths, DM., Quirk, L., Brownrigg, A. and Croot K. (2002) Effects of Essential Oils and Touch on Resistance to Nursing Care Procedures and Other Dementia-Related Behaviors in a Residential Care Facility, *The International Journal of Aromatherapy*, 12(1), 22-29.

Brodaty, H., Connors, M. H., Xu, J., Woodward, M. and Ames, D. (2014) Predictors of Institutionalization in Dementia: A Three Year Longitudinal Study, Journal of Alzheimer's Disease, 40(1), 221-226.

Christenson, AM., Buchanan, JA., Houlihan, D. and Wanzek, M. (2011) Command Use and Compliance in Staff Communication With Elderly Residents of Long-Term care Facilities, *Behavior Therapy*, 42, 47-58.

Chou, W-Y., Waszynski, C., Kessler, J., Chaing, Y-C. and Clarkson, P.J. (2016) Using positive images to manage resistance-to-care and combative behaviors in nursing home residents with dementia: A pilot study, *Geriatric Nursing*, 37(215-220).

Clark, ME., Lipe, AW. and Bilbrey, M. (1998) Use of Music to Decrease Aggressive Behaviors in People With Dementia, *Journal of Gerontological Nursing*, 10-17. Davies, HD., Sridhar, SB., Newkirk, LA., Beaudreau, SA. and O'Hara, R. (2012) Gender differences in sexual behaviors of AD patients and their relationship to spousal caregiver well-being, Aging and Mental health, 16(1): 89-101.

Dunn, JC., Thiru-Chelvam, B. and Beck, CHM. (2002) Bathing - Pleasure or Pain? *The Journal of Gerontological Nursing*, 28(11), 6-13.

Engstrom, G. and Hammar, LM. (2012) Humming as a potential tool for facilitating feeding situations between persons with dementia and their caregiver: a single case study, *Music and Medicine*, 4(4), 231-236.

Edvardsson, D., Winblad, B. and Sandman, P.O. (2008) Person-centred care of people with severe Alzheimer's Disease: current status and ways forward. The Lancet Neurology, 7(4), 362-367.

Fauth, E.B., Femia, E.E. and Zarit, S.H. (2016) Resistiveness to Care during Assistance with Activities of Daily Living in Non-institutionalized Persons with Dementia: Associations with Informal Caregivers' Stress and Well-being, Aging and Mental Health, 20(9); 888-898.

Featherstone, K., Northcott, A. and Bridges, J. (2019) Routines of resistance: An ethnography of the care of people living with dementia in acute hospital wards and its consequences, *International Journal of Nursing Studies*, 96, 53-60.

Froggatt, K., Best, A., Bunn, F., Burnside, G., Coast, J., Dunleavy, L., et al. (2020) A group intervention to improve quality of life for people with advanced dementia living in care homes: the Namaste feasibility cluster RCT, *Health Technol Assess*, 24(6), 1-140.

Galik, E., Resnick, B., Vigne, E., Dee Holmes, S. and nalls, V. (2016) Reliability and validity of the Resistiveness to Care Scale among cognitively impaired older adults. JAMDA.

Gozalo, P., Prakash, S., Qato, DM, Sloane, PD. and Mor V. (2014) Effect of Bathing Without a Battle Training Intervention on Bathing-Associated Physical and Verbal Outcomes in Nursing Home Residents with Dementia: A Randomized Crossover Diffusion Study, *Journal of the American Geriatric Society*, 62, 797-804.

Gray, SG. and Clair, AA. (2002) Influence of aromatherapy on medication administration to residential-care residents with dementia and behavioral challenges, *American Journal of Alzheimer's Disease and Other Dementias*, 17(3), 169-174.

Hallberg, IR, Holst, G., Nordmark, A. and Edberg, A-K. (1995) Cooperation During Morning Care Between Nurses and Severely Demented Institutionalized Patients, *Clinical Nursing Research*, 4(1), 78-104.

Hammar, LM., Emami, A., Engstrom, G. and Gotell. (2010<sup>a</sup>) Communicating through caregiver singing during morning care situations in dementia care, *Scandinavian Journal of Caring Sciences*, 25, 160-168.

Hammar, LM., Emami, A., Gotell, E. and Engstrom, E. (2010<sup>b</sup>) The impact of caregivers' singing on expressions of emotion and resistance during morning care situations in persons with dementia: an intervention in dementia care, *Journal of Clinical Nursing*, 20, 969-978.

Harwood, RH., O'Brien, R., Goldberg, SE., Allwood, R., Pilnick, A., Beeke, S., Thompson, L., Murray, M., Parry, R., Kearney, R., Baxindale, B., Saritain, K. and Schneider, J. (2018) Communication between people living with dementia and healthcare practitioners in hospital: developing and evaluating a staff training intervention. The VOICE Study, *Health Services and Delivery Research*, No. 6.41

Herman, RE. and Williams, KN. (2009) Elderspeak's influence on Resistiveness to Care: Focus on Behavioral Events, *American Journal of Alzheimer's Disease and Other Dementias*, 24(5), 417-423.

Hicks-Moore, SL. (2005) Relaxing Music at Mealtime in Nursing Homes: effects on agitated patients with dementia, *J Gerontol Nurs*, 31(12):26-32.

Hoffmann, TC., Glasziou, PP., Boutron, I., Milne, R., Perera, R., Moher, D. et al. (2014) Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide, *BMJ*, 348:g1687

Hoeffer, B., Talerico, KA., Rasin, J., Mitchell, M., Stewart, BJ., McKenzie, D., Barrick, AL., Rader, J. and Sloane, PD. (2006) Assisting Cognitively Impared Nursing Home Residents With Bathing: Effects of Two Bathing Interventions on Caregiving, *The Gerontologist*, 46(4), 524-532.

Ishii, S., Streim, J.E. and Saliba, D. (2012) A Conceptual Framework for Rejection of Care behaviours: review of the literature and analysis of role of dementia severity, J Am Med Dir Assoc, 13(1) 11-23 e1-2.

Jablonski, RA., Therrien, B., Mahoney, EK., Kolanowski, A., Gabello, M. and Brock, A. (2011) An intervention to reduce care-resistant behavior in persons with dementia during oral hygiene: a pilot study, Spec Care Dentist, 31(3), 77-87.

Jablonksi, RA., Kolanowski, AM., Azuero, A., Winstead, V., Jones-Townsend, C. and Geisinger, ML. (2018) Randomised Clinical Trial: Efficacy of strategies to provide oral hygiene activities to nursing home residents with dementia who resist mouth care, Gerodontology, 35: 365-375.

Jablonski-Jaudon, RA., Kolanowski, AM., Winstead, V., Jones-Townsend, C. and Azuero, A. (2016) Maturation of the MOUTh Intervention: From Reducing Threat to Relationship-Centred Care, *Journal of Gerontological Nursing*, 42(3), 15-23.

Joanna Briggs Institute (2017) Critical Appraisal Tools, Available from: https://joannabriggs.org/critical\_appraisal\_tools (accessed 20.10.2019).

Johnson, D. K., Niedens, M., Wilson, J. R., Swartzendruber, L., Yeager, A. and Jones, K. (2013) Treatment outcomes of a crisis intervention program for dementia with severe psychiatric complications: the Kansas bridge project, The Gerontologist, 53(1).

Karlin, BE., Visnic, S., Shealy McGee, J. and Teri, L. (2013) Results From the Multisite Implementation of STAR-VA: A Multicomponent Psychosocial Intervention for Managing Challenging Dementia-Related Behaviors of Veterans, *Psychological Services*,11(2):200-8. doi: 10.1037/a0033683

Kim H., Chang M., Rose K. & Kim S. (2012) Predictors of caregiver burden in caregivers of individuals with dementia. Journal of Advanced Nursing 68(4), 846–855. doi: 10.1111/j.1365-2648.2011.05787.x

Konno, R., Kang, H.S. and Makimoto, K. (2014) A best evidence review of intervention studies for minimizing resistance-to-care behaviours for older adults with dementia in nursing homes, Journal of Advanced Nursing. 70(10), 2167-2180.

Krolak-Salmon, P., Roubaud, C., Finne-Soveri, H., Riolacci-Dhoyen, N., Richard, G., Rouch, I., Leperre-Desplanques, A. and Dauphinot, V. (2016) Evaluation of a mobile team dedicated to behavioural disorders as recommended by the Alzheimer Cooperative Valuation in Europe joint action: Observational cohort study, European Journal of Neurology, 23(5).

Loko, A., Coudeyre, E., Guetin, S., Jarzebowski, W. and Belmin, J. (2018) Letter to the Editor: Effects of standardized musical intervention on refusal of care and aggression during toileting in people with institutionalized neurocognitive disorders, *Annals of Physical and Rehabilitation Medicine*, 61(421-423).

Mickus, MA., Wagenaar, DB., Averill, M., Colenda, CC., Gardiner, G. and Luo, Z. (2002) Developing Effective Bathing Strategies for Reducing Problematic Behavior for Residents With Dementia: The PRIDE Approach, *Journal of Mental Health and Aging*, 8(1), 37-43.

Moher, D., Liberati, A., Tetzlaff, J., Altman, DG. and the PRISMA Group (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement, *BMJ*, 339:b2535 doi: https://doi.org/10.1136/bmj.b2535

O'Connor, CM., Smith, R., Nott, MT., Lorang, C. and Mathews, RM. (2011) Using Video Simulated Presence to reduce resistance to care and increase participation of adults with dementia, *American Journal of Alzheimer's Disease & Other Dementias*, 26(4), 317-325.

Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rogers M, Britten N, with Roen K, Duffy S (2006) Guidance on the Conduct of Narrative Synthesis in Systematic Reviews: A Product from the ESRC Methods Programme. Available on request from:

http://www.lancaster.ac.uk/shm/research/nssr/research/dissemination/publications.php, Accessed on October 31, 2016.

Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., Wittenberg, R., Adelaja, B., Hu, B., King, D., Rehill, A. and Salimkumar, D. (2014) Dementia UK: Update, Second edition, Alzheimer's Society. Richeson, NE. and Neill, DJ. (2004) Therapeutic recreation music intervention to decrease mealtime agitation and increase food intake in older adults with dementia, *American Journal of Recreation Therapy*, 37-41.

Rogers, JC., Holm, MB., Burgio, LD., Granieri, E., Hsu, C., Hardin, M. and McDowell, J. (1999) Improving Morning Care Routines of Nursing Home Residents with Dementia, *Journal of the American Geriatrics Society*, 47, 1049-1057.

Rowe, M. and Alfred, D. (1999) The Effectiveness of Slow-Stroke Massage in Diffusing Agitated Behaviors in Individuals With Alzheimer's Disease, *Journal of Gerontological Nursing*, 25(6), 22-34.

Sidani, S., Streiner, D. and LeClerc, C. (2011) Evaluating the Effectiveness of the abilities-focused approach to morning care of people with dementia, *International Journal of Older People Nursing*, 37-45.

Simard, J. (2017) Help me, help me, Annals of Palliative Medicine, 6(4), 405-407.

Sloane, PD., Hoeffer, B., Mitchell, M., McKenzie, DA., Barrick, AL., Radar, J., Stewart, BJ., Talerico, KA., Rasin, JH., Zink, RC. And Koch, GC. (2004) Effect of Person-Centred Showering and the Towel Bath on Bathing-Associated Aggression, Agitation, and Discomfort in Nursing Home Residents with Dementia: A Randomized, Controlled Trial, *Journal of the American Geriatric Society* 52, 1795-1804.

Sloane, PD., Hoeffer., B. and Somboontanont, W. (2006) Bathing without a battle: Providing more person-centred experiences for long-term care residents with dementia, *Research and Practice in Alzheimer's Disease*, 11, 294-299.

Spigelmyer, PC., Hupcey, J. and Kitko, L. (2018) A Concept Analysis of Resistiveness to Care, Clinical Nursing Research, 1-18. https://doi.org/10.1177/1054773818789862.

Suzuki, M., Tatsumi, A., Otsuka, T., Kikuchi, K., Mizuta, A., Makino, K., ... Saruhara, T. (2010). Physical and Psychological Effects of 6-Week Tactile Massage on Elderly Patients With Severe Dementia. American Journal of Alzheimer's Disease & Other Dementias, 680–686.

Thomas, DW., Heitman, RJ. and Alexander, T. (1997) The Effects of Music on Bathing Cooperation for Residents with Dementia, *Journal of Music Therapy*, XXXIV(4), 246-259.

Thomas, P., Ingrand, P., Lalloue, F., Hazif-Thomas, C., Billon, R., Viéban, F. Clément J-P. (2004) and Reasons of informal caregivers for institutionalising dementia patients previously living at home: the Pixel study, International Journal of Geratric Psychiatry, 19(2), 127-135.

Volcier, L., Bass, E.A. and Luther, S.L. (2007) Agitation and resistiveness to care are two separate behavioral syndromes of dementia. Journal of the American Medical Directors Association. 8(8), 527-532.

Volicer, L. and Hurley, A. (2015) Assessment Scales for Advanced Dementia, Health Professions Press: Baltimore.

Volicer, L., Van der Steen, J.T. and Frijters, D.H.M. (2009) Modifiable Factors Related to Abusive Behaviours in Nursing Home Residents with Dementia. JAMDA, 617-622.

Watt, J.A., Goodarzi, Z., Veroniki, A.A., Nincic, V., Khan, P.A., Ghassemi, M., Thompson, Y., Tricco, A.C., Straus, S.E. (2019) Comparative Efficacy of Interventions for Aggressive and Agitated Behaviors in Dementia: A Systematic Review and Network Meta-analysis. Ann Intern Med, 171, 633–642.

Wells, DL., Dawson, P., Sidani, S., Craig, D. and Pringle, D. (2000) Effects of an Abilities Focused Program of Morning Care on Residents Who Have Dementia and On Caregivers, *Advanced Geriatrics Nursing Practice*, 48, 442-449.

Whall, AL., Black, ME., Groh, CJ., Yankou, DJ., Kupferschmid, BJ. and Foster, NL. (1997) The effect of natural environments upon agitation and aggression in late stage dementia patients, American *Journal of Alzheimer's Disease*, 216-220.

Williams, KN. and Herman, RE. (2011) Linking Resident Behavior to Dementia Care Communication: Effects of Emotional Tone, *Behavior Therapy*, 42(1), 42-46.

Williams, KH., Herman, R., Gajweski, B. and Wilson, K. (2009) Elderspeak Communication: Impact on Dementia Care, *American Journal of Alzheimer's Disease and Other Dementias*, 24(1), 11-20.

Williams, KN., Perkhounkova, Y., Herman, R. and Bossen, A. (2017) A Communication Intervention to Reduce Resistiveness in Dementia Care: A Cluster Randomized Controlled Trial, *Gerontologist*, 57(4), 707-718.

Zwingmann, I., Hoffmann, W., Michalowsky, B., Dreier-Wolfgramm, A., Hertel, J., Wucherer, D., Eichler, T., Killmann, I., Thiel, F., Teipel, S. and Thyrian, JR. (2017) Supporting family dementia caregivers: testing the efficacy of dementia care management on multifaceted caregivers' burden, *Aging & Mental Health*, 22(7), 889-896. Refusals of personal care in dementia: Systematic Review