




REVIEW ARTICLE

# Family involvement with care homes following placement of a relative living with dementia: a review

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## Abstract

This review updated a previous review [Gaugler JE (2005) Family involvement in residential long-term care: a synthesis and critical review. *Aging and Mental Health* 9, 105–118] and focused on dementia. Fourteen years of development in family involvement with care homes following placement of a relative was explored. The review aimed to investigate two questions: (1) What types of involvement do families have with care homes following placement of people living with dementia? (2) Which factors influence family involvement with care homes? PsycINFO, MEDLINE and CINAHL Plus were searched for publications between January 2005 and December 2018. Thirty-three papers representing 30 studies were included. Papers were appraised using a quality rating tool designed for use with mixed study designs. Studies were of a reasonable quality though some weaknesses included single-site samples, high attrition rates and poor reporting. Twenty-eight papers highlighted types of involvement including collaboration, family–staff relationship development, decision making and visiting. Twenty-five papers pertained to factors influencing involvement, which included outcome of care quality evaluation, wish for recognition and sense of integration into the care team. Type of family involvement has changed over time with increased emphasis on families' desire for partnership, to be active rather than passive advocates, and to focus on care monitoring and evaluation. Seven themes of family involvement activities are featured and a non-linear process is proposed. When compared to patient and family-centred care principles, an analysis of family involvement types found good fit overall and potential for framework improvements. Over 30 diverse factors influence inter-family variation in the level and nature of family involvement. Consideration of these factors and resolution of the gaps in evidence, including intergenerational and cultural concerns, can improve care home facilitation of family participation. This dementia-specific review is a comprehensive timely complement to Gaugler's seminal work about older adults in care.

**Keywords:** family involvement and participation; family–staff partnership; family visits and contact; dementia; systematic review; influential factors and involvement types; residential; nursing and care homes; person-centred care (PCC); family-centred care (FCC)

## Introduction

Family involvement (FI) with care homes following placement of a relative living with dementia is vital in our current care climate. FI forms part of the recommended person-centred care (PCC) approach (van der Steen *et al.*, 2014; National Institute for Health and Care Excellence (NICE), 2018) and has been linked with positive outcomes for residents, families and staff (Maas *et al.*, 2004; Castro-Monteiro *et al.*, 2016). In the United Kingdom (UK) and following the Winterbourne View (Department of Health, 2012) and Francis (The Mid-Staffordshire NHS Foundation Trust, 2013) reports, FI is central to ensuring increased transparency and partnership between care provider and client (Department of Health, 2013; van der Steen *et al.*, 2014; Care Quality Commission (CQC), 2015) alongside national care quality assessment.

Approximately one-third to one-half of people living with dementia in high-income countries, and approximately 6 per cent of those in low- and middle-income countries are cared for in long-term care facilities (Prince *et al.*, 2013). With 46.8 million people worldwide living with dementia in 2015 and this number predicted to double every 20 years for the foreseeable future, it is probable that residents living with dementia will remain the majority service user group in care homes (Alzheimer's Disease International, 2015).

This prediction is additionally credible as cultural and social norms begin to change in families and societies, such as China and East Asia where, until recently, the prevalent attitude has been to care for relatives at home (Yamashita *et al.*, 2013; Zhang *et al.*, 2020). The rise of increasingly individualised rather than collective approaches to family working and living arrangements has meant intergenerational families are no longer universally living together. Despite lack of suitable and available institutions, stigma and other barriers to engagement (Zhang *et al.*, 2020), demand for care homes is likely to increase from families, with diverse cultures, who have not previously sought support for relatives living with dementia.

Care providers may increasingly turn to and benefit from families' assistance with facilitation of a high quality of care for residents (Port *et al.*, 2003). While not every care home resident living with dementia has family or has family available and willing to engage (van der Steen *et al.*, 2012), understanding the nature and impact of FI with care homes may provide insights into improved care processes that benefit all residents.

## Theory, person and family-centred care

FI has been described as a multi-dimensional construct that entails visiting, socio-emotional care, advocacy and the provision of personal care (Gaugler, 2005; Reid *et al.*, 2007). Theoretical frameworks for FI have predominantly focused on person–environment fit and interaction (Powell *et al.*, 1975; Kahana *et al.*, 2003), role theory (Biddle, 1986), family systems theory (Minuchin, 1974) and stress

theory (Pearlin *et al.*, 1990). Theories posit that person–environment fit, interaction and patterns of communication alter over time, for residents living with dementia, family and staff. Environmental interventions are tried in the pursuit of stress reduction and to meet the evolving needs of the resident as dementia progresses. Families are challenged to adapt their intergenerationally established and stable patterns for communication and interrelation, to cope with a relative's long-term care placement. Levels of stress and burden change as social positions and care-giver roles and role nature (the number of roles, intensity, ambiguity, expectations, skill demand, conflict, norms and behaviours) change. While adapting, families are challenged with ensuring care homes accommodate their cultural and heritage-related differences in family participation. A new area of importance, further research into cultural drivers of FI is needed (McCreedy *et al.*, 2018).

FI and PCC are accepted standards in dementia service provision (Brooker, 2004) and their emphasis appears to somewhat lessen the impact of the challenges for families (especially as they encompass much more than medical concerns). However, demonstrating evidence for psycho-social interventions such as PCC is far from straightforward (Fazio *et al.*, 2018) and it is similarly difficult for FI. To underline this point, few common definitions of PCC exist (Kitson *et al.*, 2013); for examples, see Brooker (2004) and Vernooij-Dassen and Moniz-Cook (2016). There are common themes in the application of PCC, though emphasis has varied (Kitson *et al.*, 2013) and specific person-centred activities can be infrequent (Cooper *et al.*, 2018). PCC themes have intermittently involved family carers (Kitson *et al.*, 2013). Recently, after a review of the literature describing PCC for people living with dementia, Fazio *et al.* (2018) recommended six practices for PCC including *Create and maintain a supportive community for individuals, families and staff*.

In an extension of PCC, family-centred care (FCC) has grown in attention and has been found effective in the dementia field (one example is the study by Maio *et al.*, 2016). Again, debate remains about the definition of FCC (Shields, 2015; Giosa *et al.*, 2019; Hao and Ruggiano, 2020) and its merits are not without controversy (Shields, 2010). However, a FCC approach is more likely to mitigate family challenges, all while maintaining best practice of care for relatives living with dementia.

Originating in paediatrics, FCC is characterised by several principles, including (a) respect and incorporation of family perspectives, choices and cultural preferences; (b) helpful, affirming sharing of timely, complete and unbiased information with families; (c) families to be encouraged and supported to participate in care and decision making; (d) collaboration with families in policy and programme development, implementation and evaluation, and care delivery (Institute of Patient and Family Centred Care (IPFCC), 2020).

After a review of older adults' care preferences, Etkind *et al.* (2018) proposed older people with illnesses and their families should be considered together as a *care unit*. The NICE (2018) definition of PCC reflects this. While it does not outline the FCC components above, it acknowledges the human value of family in its first principle and makes an additional reference to the importance of accounting for family carer needs. FCC and related research is necessary while demand for care homes rises, staff increase their reliance on families to fill gaps in service provision and optimum care standards are sought. With PCC and FCC principles in mind,

what does the existing research and literature tell us about dementia-specific FI with care homes?

### **Existing literature reviews**

A major review of approximately 100 studies pertaining to FI in residential long-term care was previously published (Gaugler, 2005). It focused primarily on US-based research and reference was made to eight studies involving residents living with dementia. Findings highlighted that family members continued to participate in their relatives' lives (though the frequency and duration of visits fluctuated) and types of involvement beyond activities of daily living (ADL) included supervision and monitoring of quality of care. Factors found to influence visits and involvement included stronger family–resident relationships, social resources, resident length of stay and frequency of pre-placement behavioural difficulties. The review supported the link between family visits and benefits for residents such as reduced infections and hospitalisations. With the synthesis being over 14 years old, it is not known if there have been any changes in this arena.

Petriwskyj *et al.* (2014) conducted a review of 26 studies published between 1990 and 2013. This review offers an insight into the advocacy role of family members and factors influencing participation. However, it was limited to decision-making aspects of FI and primarily focused on choices relating to medical issues.

A meta-ethnographic review by Graneheim *et al.* (2014) involving ten studies found family care-givers described their experiences of relinquishing the care of a person living with dementia as a process. Authors proposed family adaptation to relative placement in care homes can be facilitated when families are recognised as care partners. However, the review emphasis was on the emotional strain family care-givers face through the transition.

A review by Law *et al.* (2017) focused on family satisfaction with staff and yielded 14 studies. They highlighted families' preference for shared responsibility for care, ongoing relationships with staff and effective staff communication with family. Types of involvement and factors influencing FI with care homes were not specifically examined.

### **Current literature review**

Our literature review developed Gaugler's (2005) synthesis of FI with care homes by providing an update on global developments over the last 14 years with specific reference to families of residents living with dementia.

### **Literature review questions**

The following research questions were addressed:

- (1) What types of involvement do families have with care homes following placement of a person living with dementia?
- (2) Which factors influence FI with care homes following placement of a person living with dementia?

In addition to the multiple points raised in the introduction and theory section, asking these 'back to basics' questions was important for multiple reasons. Existing reviews are outdated or have focused on medical choices, role adjustment or satisfaction with staff. Therefore, this review provides a timely update for the existing evidence base; developments are highlighted, previously made recommendations that have yet to be pursued are discovered and the current literature is checked for how well it represents the global concern.

To our knowledge, there is no comprehensive reference list and discussion of these topics focused on dementia and care homes. The authors' review fills a gap and sets a baseline for future dementia-specific reviews. It also prevents the literature base from assuming or implying FI with care homes is the same regardless of whether dementia is involved or not.

Our exploration aims to shape the foundations of and inform future developments in PCC and FCC care home approaches, policies and programmes; it will go beyond medical decisions. Family-centred research is crucial because it embodies the first principle of FCC; dignity and respect for older adult and family wishes, both of whom prefer families are involved in care (Petriwksyj *et al.*, 2014; Etkind *et al.*, 2018). This review will enable researchers and care homes to understand what the family actually does, and give insight into what influences this activity and consider these factors when creating and delivering standardised *versus* customised residential dementia care services.

Finally, this review is important because while its research questions stand alone, it also compliments another dementia-focused review by Hayward, J.K., Gould, C., Palluotto, E., Kitson, E.C., Fisher, E.R. and Spector, A. (submitted) spanning January 2005 to April 2021. Measures of FI and interventions designed to foster FI with care homes were explored. Studies reporting the impact of FI on resident behavioural and psychological symptoms of dementia (BPSD) were also investigated. The specific research questions asked were: (a) which interventions concerning FI have been evaluated? and (b) does FI within care homes have a positive effect on resident quality of life and BPSD symptoms of dementia? While the research questions in both reviews are distinct, together they provide a comprehensive picture of the available FI evidence base.

## Method

This literature review is based on the University of York – Centre for Reviews and Dissemination (2009) guidelines on conducting systematic literature reviews in health care. The full inclusion and exclusion criteria were as follows.

### Inclusion criteria

- Randomised controlled trial designs, quasi-experimental designs, interrupted time-series designs with the family member or family member and their relative as own comparison and qualitative studies.
- Families with a relative living with dementia residing in a residential care home or nursing home.
- Studies where  $N \geq 10$ .

- Published in English in peer-reviewed journals between 2005 and 2018.
- Training or interventions for families (or families and residents) that pertained to FI or partnership with long-term care providers and related resident psycho-social outcomes.

### **Exclusion criteria**

- Studies, training or interventions solely set in home care, assisted community living or inpatient settings.
- Training or interventions for staff and/or residents that did not involve families.
- Family interventions focused solely on physical, medical or non-psychological outcomes, e.g. decisions about psychotropic medication.
- Studies focused exclusively on care-giver burden, stress or wellbeing.
- End-of-life or advanced care planning studies where FI was not of primary interest.

### **Search strategy**

In January 2016 databases PsycINFO, MEDLINE and CINAHL Plus were searched for papers published between 2005 and 2015. This search was extended in May 2019 to include 2016–2018. Key terms were entered into Keyword, Subject heading and Ovid .mp searches in order to find studies pertaining to FI ('family', 'families', 'informal caregiver', 'involvement', 'engagement', 'participation', 'role/roles', 'interaction', 'visit/visiting') within a care home setting ('care home', 'residential care', 'residential aged care', 'nursing home', 'skilled nursing facility/facilities', 'institutionalisation', 'long-term care') for relatives with a diagnosis of dementia ('dementia', 'Alzheimer's', 'Alzheimer's disease'). Key phrases were also used to ensure a broad search ('working with families' and 'family-staff relationships').

Three authors reviewed the papers ensuing from the search by title, abstract and full paper according to the inclusion and exclusion criteria. A snowball sampling strategy was used as reference lists from systematic reviews and each selected paper was examined to identify additional studies.

### **Quality rating**

The Mixed Methods Appraisal Tool (MMAT) – Version 2011 developed by Pluye *et al.* (2011) was chosen to assess the quality of studies as it enables the rating of studies with various methodologies. Permission to use the MMAT was obtained from the authors. Four researchers applied the tool and sought consensus when any differences arose.

Ratings of quality were based on a 21-criteria checklist involving two screening questions for all studies and five sections; qualitative (four criteria), quantitative (randomised, non-randomised and descriptive, all with four criteria each) and mixed methods (three criteria). The sections and sub-sets of criteria were applied according to the type of study being reviewed. Responses to rating questions included 'Yes', 'No' and 'Can't tell'.

Papers received a score denoted by descriptors \*, \*\*, \*\*\* and \*\*\*\*. For qualitative and quantitative studies, this score is the number of criteria met divided by four with scores varying from 25 per cent (\*) with one criterion met to 100 per cent (\*\*\*\*)

with all criteria met. For mixed-methods studies, overall quality is the lowest score of the study components. Criteria included quality of data sources, consideration of researcher influence and sample recruitment bias, as well as data outcome completion and dropout rates.

### **Classification and analysis**

The selected studies were classified according to the research questions posed and divided into two tables by methodology. A synopsis and appraisal result for all included papers are provided. Results were analysed and reported in relation to PCC and FCC frameworks. A convergent approach (Creswell *et al.*, 2011) was predominantly employed for reporting the review findings in relation to each research question.

## **Results**

### **Included studies**

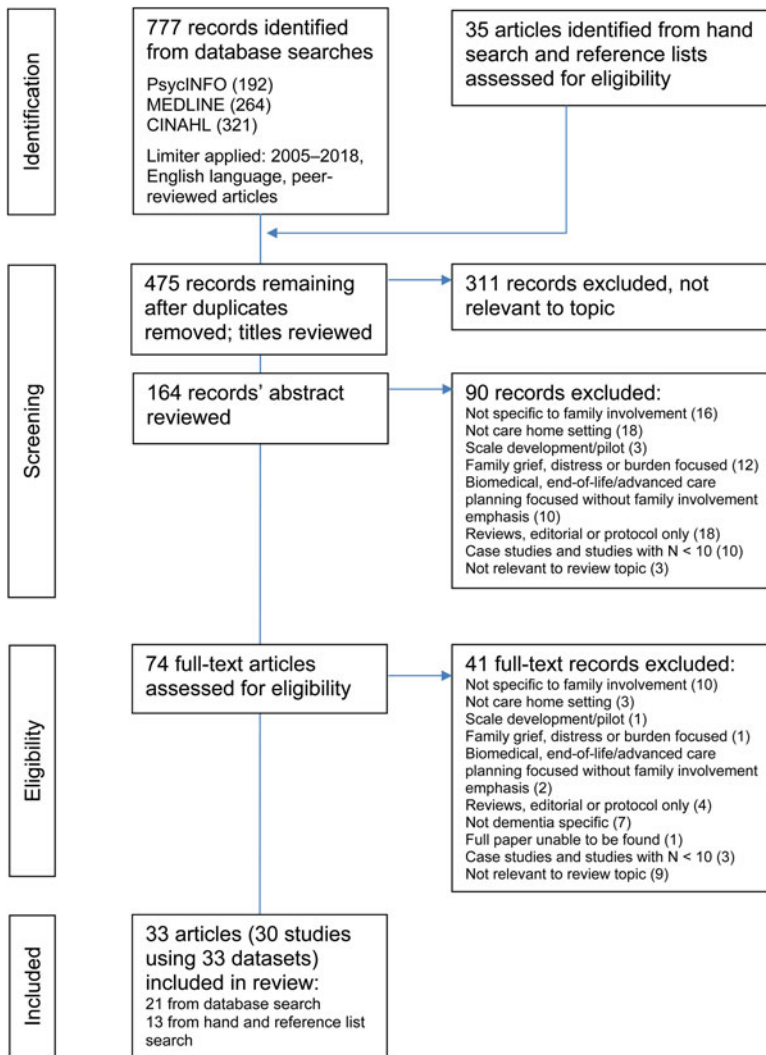
A total of 475 papers were identified from the database searches, 311 of which were excluded based on the above exclusion criteria and a review of titles, as they were deemed unrelated to the review topic. Following an abstract review, a further 90 papers were excluded: three were deemed unrelated to the review topic, 16 were not specific to FI, 18 related to non-care home settings, three related to scale development, 12 focused on care-giver grief or burden, ten pertained to biomedical, end-of-life and advanced care planning without emphasis on FI, 18 were reviews, editorial or protocols only, and ten involved samples of less than ten.

The paper identification and eligibility process is depicted in [Figure 1](#) and shows that following a full-text paper review ( $N = 74$ ), a further 41 papers were excluded. Of the 35 additional papers identified through hand and reference list searches, two-thirds were excluded ( $N = 22$ ). Thirty-three papers remained for inclusion. Research was primarily conducted in United States of America (USA;  $N = 10$ ), Canada ( $N = 5$ ) and Australia ( $N = 5$ ). Cross-country studies included Italy and the Netherlands ( $N = 1$ ). Sweden ( $N = 3$ ), Norway ( $N = 3$ ), the UK ( $N = 2$ ) and a paper from each of Belgium, Japan, Israel and Taiwan were found. The papers reported studies with quantitative or mixed-methods ( $N = 16$ ) and qualitative designs ( $N = 17$ ).

Two papers reported results from the same study (Bramble *et al.*, 2009, 2011). Data from a study were investigated in three different ways and reported separately (Dobbs *et al.*, 2005; Port *et al.*, 2005; Zimmerman *et al.*, 2005). Therefore, 33 papers representing 30 studies drawn from 33 datasets were included in this review. The included papers are classified in [Tables 1](#) and [2](#).

### **Study design and quality**

Quality ratings ranged from \* to \*\*\*\* (see [Table 3](#)), indicating a wide variation in study quality. Despite this, most studies scored \*\*\* or above and showed methodological strengths in setting out study objectives, including multiple sites in their



**Figure 1.** Flowchart of literature identification and eligibility.

Note: ADL: activities of daily living.

samples, applying site randomisation, describing analyses, use of verification procedures and drawing conclusions in line with results. The remaining studies rated in the review were of low to medium quality, receiving ratings between \* and \*\*. Generally, studies had appropriate study designs for the questions posed and conclusions that were supported by their results. However, some studies did not appear to consider power, had sample sizes that were too small for analyses conducted and had high attrition rates, while the quality of other studies were reduced by incomplete reporting of data collection or results.



**Table 1.** Papers reporting studies involving family involvement (FI) types and/or influences with a quantitative or mixed-method design

| Authors   | Method, approach and setting   | N  | Key FI domain, measures and time-points   | Key results  | Quality rating and comments   |
|---|--|--|---|--|---|
| Ampe <i>et al.</i> , 2016 (Belgium)<br>RQ: 1 and 2    | Observational cross-sectional study<br>Examined ACP policy, degree of involvement of residents and families and the relationship between policy and practice<br>20 care homes        | <i>Family</i><br>13<br><i>Residents</i><br>16<br><i>Staff</i><br>153 | <i>Family:</i> Relevant items within ACP audit 45-item questionnaire including conversations with families regarding their preferences, communication in crisis situations, communication in palliative care phase; OPTION<br><i>Resident:</i> Relevant items within ACP audit questionnaire including conversations at time of admission; OPTION<br>Baseline | No association found between policy and practice about decision making. Staff used baseline skills only when involving residents/families  | MMAT: ****<br><i>Positive:</i> Triangulation of measures, sample size, well-defined/operationalised measures reliability and validity checks<br><i>Negative:</i> Care home size, dementia phase, staff duration not reported. Families and residents not directly studied, further validation of audit measure required |
| Boogaard <i>et al.</i> , 2017 (Israel)<br>RQ: 1 and 2 | Correlational (cross-sectional)<br>Investigated trust in health professionals among family care-givers of nursing home residents with advanced dementia<br>28 care homes (86% urban) | <i>Family</i><br>214   | <i>Family:</i> Satisfaction with care (EOLD-SWC, FPPFC); trust (3 role-based items); involvement with care (FIC); care burden (ZBI)<br><i>Resident:</i> Symptom management (EOLD-SM), dementia severity (BANS-S)<br>Baseline  | FI (based on at least one visit a fortnight) related to overall trust in health professionals (not significant when other variables accounted for). Families scored 21/40 on involvement measure. Higher family satisfaction with care and positive appraisals of family-staff communication significantly linked with trust | MMAT:****<br><i>Positive:</i> Large sample from multiple sites, clustering adjustments made, estimate of variance reported<br><i>Negative:</i> Staff years of experience absent, no power analysis or description of missing data   |
| Bramble <i>et al.</i> , 2011                          |  | <i>Family</i><br>57  | <i>Family:</i> Knowledge (FKOD); stress (FPCR); satisfaction  | Significant increase in both family and staff  | MMAT: ****<br><i>Positive:</i> Randomised sites,  |

|   |   |   |   |   |   |
|---|---|---|---|---|---|
| (Australia)<br>RQ: 2                                  | CRCT (mixed methods)<br>FIC intervention<br>2 long-term care facilities   | Staff<br>59                                       | (FPCT)<br>Staff: Knowledge (SKOD);<br>stress (SPCR; CSI); attitudes<br>towards family (AFC)<br>Baseline, 1, 5 and 9 months  | knowledge of dementia,<br>significant decrease in<br>family satisfaction<br>regarding staff<br>consideration and<br>management effectiveness  | blinding, power and<br>attrition aims<br><i>Negative:</i> Small sample,<br>follow-up attrition, no<br>variance reported   |
| Cohen <i>et al.</i> ,<br>2014<br>(USA)<br>RQ: 1 and 2 | Correlational (cross-<br>sectional)<br>Investigated care-giver<br>involvement for residents<br>living with dementia<br>24 long-term care facilities<br>1 US state             | Family<br>467<br>Residents<br>467<br>Staff<br>381 | Family: FI visits (Murphy)<br>Resident: Cognition (MDS-<br>COGS); function (MDS-ADL);<br>function (IADL)<br>Staff: FI visits (Murphy)<br>Baseline   | Families reported<br>significantly greater visits<br>than staff, no significant<br>difference in visit<br>frequency by dementia<br>severity. Families of<br>residents living with<br>dementia spent<br>significantly more time on<br>ADL and staff discussion<br>than families of residents<br>without dementia | MMAT: ****<br><i>Positive:</i> Large sample,<br>power, measures,<br>adjustment for clustering<br>effects<br><i>Negative:</i> Visit exclusions,<br>inconsistent variance<br>reporting                    |
| Dobbs <i>et al.</i> ,<br>2005<br>(USA)<br>RQ: 1       | Correlational (cross-<br>sectional)<br>Compared dementia care<br>in residential care (RC)/<br>assisted living (AL) to care<br>homes<br>35 RC/AL, 10 care homes<br>4 US states | Family<br>400<br>Residents<br>400                 | Family: Frequency of visits<br>Resident: Activity<br>involvement (PAS-AD)<br>Baseline   | Families visited at least<br>once in the last week,<br>family assessing activities<br>and social involvement<br>was related to more<br>resident activity<br>involvement   | MMAT: ***<br><i>Positive:</i> Large sample,<br>adjustments, variance<br>reporting<br><i>Negative:</i> No description of<br>family participants, non-<br>standardised facility<br>measures, missing data |
| Grabowski<br>and Mitchell,<br>2009<br>(USA)<br>RQ: 1  | Correlational<br>(longitudinal)<br>Examined care-giver visit<br>duration and resident<br>quality EOL care<br>22 care homes<br>1 US city                                       | Family<br>323<br>Residents<br>323                 | Family: Oversight (visit<br>hours per week);<br>satisfaction with care<br>(SWC-EOLD)<br>Resident: Health and<br>dementia severity (BANS-<br>S); quality of life (QUALID);<br>quality of care (seven | Most families spent<br>between one and seven<br>hours visiting each week,<br>family satisfaction with<br>care highest in group that<br>did not visit, quality of<br>care significantly worse for  | MMAT: ***<br><i>Positive:</i> Longitudinal, large<br>sample, confound control,<br>variance and limitation<br>reporting<br><i>Negative:</i> One non-<br>representative,<br>geographical site             |

(Continued)

Table 1. (Continued.)

| Authors  | Method, approach and setting   | N   | Key FI domain, measures and time-points   | Key results  | Quality rating and comments  |
|--|--|---|---|--|--|
| Helgesen et al., 2015 (Norway)<br>RQ: 1 and 2        | Cross-sectional descriptive<br>Examined family participation in the everyday care of their loved ones<br>23 care home special care units | Family<br>233   | domains)<br>Baseline, quarterly for 18 months/death   | residents visited over 7 hours per week  | MMAT: ****<br><i>Positive:</i> Good response rate, participants randomly selected, iterative scale development referenced and piloted, considered non-responders<br><i>Negative:</i> Questionnaire is new and not been extensively validated |
| Levy-Storms and Miller-Martinez, 2005 (USA)<br>RQ: 1 | Correlational (longitudinal)<br>Investigated relationship between involvement and satisfaction with care<br>>70% care homes              | Family<br>145<br>Residents<br>145                       | Family: Satisfaction with care (11 areas); involvement (type of assistance, frequency of visits)<br>Resident: Behavioural problems (care-giver perception of resident's behavioural problems questionnaire)<br>Baseline (admission) and 12 months | Family involvement in I/ADL was associated to level of care satisfaction, frequency of visiting was not. The more that families provided I/ADL assistance at admission, the lower their level of satisfaction 1 year later | MMAT: ****<br><i>Positive:</i> Analysis description, controls, reported variance<br><i>Negative:</i> Non-standardised measures, no power analysis, self-selected sample, attrition rate  |
| Livingston et al., 2017 (UK)<br>RQ: 1 and 2          | Correlational, cross-sectional<br>Reported prevalence and determinants of agitation in residents living with                             | Family<br>1,281<br>Residents<br>1,483<br>Staff<br>1,701 | Family: Quality of life (DEMQOL), visits<br>Resident: Agitation (CMAI); quality of life (DEMQOL); dementia severity (CDR); neuropsychiatric symptoms  | Clinically significant agitation shown by 40% of residents living with dementia. Agitation was not associated with   | MMAT ****<br><i>Positive:</i> Large sample, sensitivity analyses, confound control, variance reporting, generalisability of results  |

|   | dementia<br>86 care homes  |   | (NPI)<br>Baseline   | number of visits by the<br>main family carer   | <i>Negative:</i> Possible<br>underestimation of<br>agitation level  |
|---|--|---|---|--|---|
| McCreeley<br><i>et al.</i> (2018)<br>(USA)<br>RQ: 1 and 2 | Descriptive, cross-<br>sectional<br>Described the prevalence<br>of family participation in<br>the care planning process<br>for nursing home<br>residents living with<br>dementia<br>292 care homes | <i>Residents</i><br>18,552                      | <i>Family:</i> Resident<br>Assessment Instrument<br>resulting in minimum<br>dataset (participation in<br>care planning – yes/no)<br><i>Resident:</i> Resident<br>Assessment Instrument<br>resulting in minimum<br>dataset (including<br>cognitive function (CFS);<br>behavioural, psychosis-<br>related and physical<br>symptoms)<br>Baseline | Family participation in<br>assessments is low and<br>varied by degree of<br>resident cognitive<br>impairment. Residents<br>living with dementia<br>diagnosis significantly<br>more likely to have FI than<br>residents with intact<br>cognition. Over 50% of<br>residents living with<br>severe dementia had no<br>family representation in<br>care planning | MMAT: ****<br><i>Positive:</i> Large sample,<br>detailed demographics,<br>adjustment for clustering<br>and multiple variables,<br>variance reporting<br><i>Negative:</i> Sample from 1<br>large for-profit nursing<br>home system therefore no<br>generalisability;<br>participation measure<br>ambiguity |
| Minematsu,<br>2006<br>(Japan)<br>RQ: 1 and 2              | Correlational<br>(longitudinal)<br>Investigated family visits<br>and BPSD<br>1 care home   | <i>Residents</i><br>67                          | <i>Family:</i> Hours per week<br>visiting/talking<br><i>Resident:</i> Cognition (HDS-<br>R); BPSD suppression<br>(DBD)<br>Baseline, 12 months   | Majority of residents<br>visited between 0 and 10<br>times per month on<br>average, frequency of<br>visits associated with<br>positive change in HDS-R<br>and DBD in residents with<br>initial moderate HDS-R,<br>change was lower where<br>visit frequency was above<br>average   | MMAT: *<br><i>Positive:</i> Longitudinal (12<br>months), measures,<br>description of analysis,<br>multiple appraisers<br><i>Negative:</i> Small single-site<br>sample, minimal<br>description of participants<br>and data collection,<br>missing measure reference<br>and limitations                     |
| Port <i>et al.</i> ,<br>2005<br>(USA)<br>RQ: 1 and 2      | Correlational (mixed-<br>methods) (cross-<br>sectional)<br>Compared dementia care<br>in residential care (RC)/<br>assisted living (AL) to care   | <i>Family</i><br>353<br><i>Residents</i><br>353 | <i>Family:</i> Involvement<br>(expenses, time visiting/<br>talking, involvement,<br>involvement preference,<br>burden, and across 8<br>activities)  | No significant difference in<br>visit/talking time or family<br>preference for higher<br>involvement, families<br>desire more involvement  | MMAT: ***<br><i>Positive:</i> Large sample,<br>description of quantitative<br>analysis, confound control,<br>randomisation within site<br><i>Negative:</i> Site type  |

(Continued)

Table 1. (Continued.)

| Authors   | Method, approach and setting   | N   | Key FI domain, measures and time-points   | Key results   | Quality rating and comments   |
|---|--|---|---|---|---|
|   | homes<br>35 RC/AL, 10 care homes<br>4 US states  |   | <i>Resident</i> : Independence (MDS-ADL); cognition (MMSE; MDS-COGS)<br>Baseline  | and assistance in being involved  | recruitment, self-report reliance, power unclear, qualitative analysis description  |
| Reid and Chappell, 2017 (Canada)<br>RQ: 1 and 2 | Descriptive<br>Investigated involvement opportunities and importance<br>18 care homes<br>3 communities   | <i>Family</i><br>135<br><i>Residents</i><br>149 | <i>Family</i> : Involvement importance (FICS-FII) and perceived opportunities for involvement and involvement congruence (FICS-T)<br>Baseline | Incongruence of opportunities over importance for seven types of involvement. A lack of opportunity for important types of involvement  | MMAT: ****<br><i>Positive</i> : Sample, power, description of sample selection, measure refinement, response rate<br><i>Negative</i> : Single informant   |
| Reinhardt <i>et al.</i> , 2015 (USA)<br>RQ: 1   | Correlational (longitudinal)<br>Investigated involvement and frequency of conversations about palliative care<br>1 care home<br>North-east USA   | <i>Family</i><br>90<br><i>Residents</i><br>90   | <i>Family</i> : Frequency of discussion with staff across seven EOL domains<br><i>Resident</i> : Cognition (CPS)<br>Baseline, 3, 6 months     | Just under half the families visited at least once per week, higher frequency of discussion was associated with higher care satisfaction  | MMAT: ***<br><i>Positive</i> : Confound control, effect size, variance reporting<br><i>Negative</i> : Single site, small sample, sample selection bias not accounted for  |
| Toles <i>et al.</i> , 2018 (USA)<br>RQ: 1       | Correlational (cross-sectional)<br>Examined links between resident and family characteristics and family decision makers' perceptions of quality of communication (QoC)<br>22 care homes<br>1 US state | <i>Family</i><br>302<br><i>Residents</i><br>302 | <i>Family</i> : QoC including involvement and interactions, demographics<br><i>Resident</i> : Demographics<br>Baseline                        | Although family decision makers for persons living with dementia rated QoC with nursing home staff higher than that with clinicians, they reported poor-quality EOL communication for both staff and clinicians; 26% of staff and 50% of clinicians did not involve family decision makers in | MMAT ****<br><i>Positive</i> : Sample size, diverse homes, prospective data collection, use of widely employed measure, adjusted for clustering effects, non-significant result included in reporting<br><i>Negative</i> : One geographical state, uncontrolled potential confounds |

|   |   |   |   |   |   |
|---|---|---|---|---|---|
|   |   |   |   | decisions about treatment residents would want  | identified, no effect size reporting  |
| Zimmerman <i>et al.</i> , 2005 (USA)<br>RQ: 1 | Correlational (longitudinal)<br>Compared dementia care in residential care (RC)/ assisted living (AL) to care homes<br>35 RC/AL, 10 care homes<br>4 US states | <i>Family</i><br>170<br><i>Residents</i><br>170 | <i>Family</i> : Frequency of visits<br><i>Resident</i> : Activity involvement (PAS-AD); quality of life (QOL in AD-activity); behaviour (DCM)<br>Baseline, 6 months | Families spent almost seven hours per week on average visiting or talking with the resident, FI was associated to higher resident quality of life | MMAT: ****<br><i>Positive</i> : Longitudinal, randomisation within site, confound adjustments, limitation reporting<br><i>Negative</i> : Missing data, no power analysis or effect size |

Notes: ACP: advanced care planning. ADL: activities of daily living. AFC: Attitudes Towards Family Checklist. BANS-S: Bedford Alzheimer’s Nursing Severity subscale. BPSD: behavioural and psychological symptoms of dementia. CDR: Clinical Dementia Rating. CFS: Cognitive Function Scale. CMAI: Cohen-Mansfield Agitation Inventory. CPS: Cognitive Performance Scale. CRCT: clustered randomised controlled trial. CSI: caregiver stress inventory. DBD: Dementia Behaviour Disturbance scale. DCM: Dementia Care Mapping. DEMQOL: Dementia Quality of Life Measure. EOL: end of life. EOLD-SM: End of Life in Dementia Scale - Symptom Management. FIC: Family Involvement in Care. FICS-FII: Those For Whom Family Involvement Is Important. FICS-T: Total Family Involvement Congruence Score. FKOD: Family Knowledge of Dementia test. FPCR: family perceptions of care-giving role. FPCT: Family Perceptions of Care Tool. FPPFC: Physician-Family Care Giver Communication. HDS-R: Hasegawa Dementia Scale-Revised. IADL: instrumental activities of daily living. I/ADL: Instrumental Activities of Daily Living scale. MDS-ADL: Minimum Data Set-Activities of Daily Living Scale. MDS-COGS: Minimum Data Set Cognition Scale. MMAT: Mixed Methods Appraisal Tool. MMSE: Mini-mental State Examination. Murphy: Murphy *et al.*, 2000 Involvement Scale. NPI: Neuropsychiatric Inventory. OPTION: Observing Patient Involvement. PAS-AD: Patient Activity Scale-Alzheimer’s Disease. QoC: quality of communication. QOL in AD-activity: Quality of Life in Alzheimer’s Disease Activity. QUALID: Quality of Life in Late-stage Dementia. UK: United Kingdom. USA: United States of America. RCT: randomised controlled trial. RQ: research question. SKOD: staff knowledge of dementia test. SPCR: staff perceptions of care-giving role. SWC-EOLD: Satisfaction with Care at the End-of-Life in Dementia Scale. ZBI: Zarit Burden Interview.

**Table 2.** Papers reporting studies involving family involvement (FI) types and or influences with a qualitative design

| Authors   | Method, approach and setting   | N  | Key domain and time-points (single unless stated)  | Key results  | Quality rating and comments  |
|---|--|--|--|--|--|
| Bramble <i>et al.</i> , 2009 (Australia)<br>RQ: 1 and 2 | Semi-structured interviews from mixed-methods study<br>Descriptive<br>2 long-term care facilities                    | <i>Family</i><br>10<br><i>Resident</i><br>10 | Meaning of being family of a relative living with dementia who is placed in long-term care                 | Family sought connection and meaning with staff, evaluation of care spanned general satisfaction with the environment, level of physical care, attitude of staff, their friendliness and obvious sense of care for the patients who are there  | MMAT: ****<br><i>Positive:</i> Description of thematic sequential analysis and steps to ensure rigour<br><i>Negative:</i> Small sample, researcher philosophy unclear  |
| Caron <i>et al.</i> , 2005 (Canada)<br>RQ: 1 and 2      | In-depth interviews<br>Narrative<br>2 long-term care facilities  | <i>Family</i><br>24<br><i>Resident</i><br>20 | Context of interactions with care providers when making end-of-life decisions                              | Four domains identified; quality of the relationship, frequency of contact, values and beliefs, and level of trust. Families seek a personalised relationship with staff   | MMAT: ****<br><i>Positive:</i> Description of data collection, bias prevention, limitations<br><i>Negative:</i> Sample site description  |
| Carter <i>et al.</i> , 2018 (UK)<br>RQ: 1 and 2         | Semi-structured interviews from mixed-methods study (embedded)<br>Descriptive with thematic analysis<br>4 care homes | <i>Family</i><br>20<br><i>Resident</i><br>20 | Family role, preparedness and experience of making decisions around care-giving and advanced care planning | Three themes identified under overarching theme of 'preparedness'. Families described their substitute decision-maker role a responsibility. Family circumstance or a medical background, perceived staff dementia-specific skills, sense of guilt, loyalty and responsibility were highlighted as influential in caring and decision making for relatives. Lack of awareness over dementia progression, disease progression being 'taboo' and care home staff not raising advanced care planning topics with families were cited as reasons for not approaching discussions | MMAT: ***<br><i>Positive:</i> Interview schedule provided, data saturation approach, reflexivity, inter-rater agreement and trustworthiness framework applied<br><i>Negative:</i> Small self-selected sample, 1 care home chain, possible bias; 12 participants completed an intervention prior to study. Closed question in schedule. Researcher stance unknown. Some ambiguity; findings/main topic. |

(Continued)

Table 2. (Continued.)

| Authors  | Method, approach and setting   | N   | Key domain and time-points (single unless stated)  | Key results   | Quality rating and comments  |
|--|--|---|--|---|--|
| Edvardsson <i>et al.</i> , 2010 (Australia)<br>RQ: 1   | Interviews, focus groups<br>3 long-term care facilities  | <i>Family</i><br>12<br><i>Staff</i><br>37 | Content of PCC   | PCC promoted a continuation of resident self and normality across five content categories including welcoming family, families aimed to develop and maintain trust in the staff to facilitate active communication about the resident, families desired that staff actively encouraged them to maintain the relationship and life they had with the resident  | MMAT: **<br><i>Positive</i> : Analysis by multiple researchers, sample variation<br><i>Negative</i> : Reflexivity, credibility, convenience sample   |
| Forsund and Ytrehus, 2018 (Norway)<br>RQ: 1 and 2      | Interviews and observations<br>Descriptive<br>Grounded theory<br>8 long-term care facilities<br>5 municipalities | <i>Family</i><br>15                       | Influences of the care home physical and social environment on spouses' opportunities to maintain relationship with partner living with dementia | Visits per resident ranged from 1 to 7 per week. Finding a place for spouses to connect in the long-term care facility was important in maintaining relationships. Access to individual rooms was important for privacy and familiarity, whereas common areas appeared more difficult to use. Proximity to health personnel was important to spouse whose partner had severe dementia in sustaining relationships | MMAT: ***<br><i>Positive</i> : Interview and observations used, theoretical sampling, philosophical approach clear, follow-up interviews undertaken<br><i>Negative</i> : Reduced care home access and high attrition rate for observations |
| Gladstone <i>et al.</i> , 2006 (Canada)<br>RQ: 1 and 2 | In-depth interviews<br>Interpretivist<br>naturalistic with thematic analysis<br>2 care homes                     | <i>Family</i><br>35                       | Family roles, activities and change factors<br>Baseline, 12 months   | Family visits increased over time and change in contact was associated with four conditions: personal, social, institutional (reduction in visits) and health (increased contacts)  | MMAT: ****<br><i>Positive</i> : Large and maximum variation sampling, longitudinal design, negative case analysis<br><i>Negative</i> : Small site sample, visit data collection unclear and reliant on self-report                         |

(Continued)



Table 2. (Continued.)

| Authors                                       | Method, approach and setting  | N            | Key domain and time-points (single unless stated)  | Key results   | Quality rating and comments  |
|---|---|--------------|--|---|--|
| Helgesen et al., 2012 (Norway)<br>RQ: 1 and 2 | Interviews<br>Grounded theory<br>3 special care units                     | Family<br>12 | Family role in patient participation process<br>Participants interviewed twice over one year | Experienced as transitions between different roles to secure the residents' wellbeing; visitor (prerequisite for other roles), spokesperson, guardian and link to outside world. Different situations triggered different kinds of role and role depended on different conditions | MMAT: ****<br><i>Positive:</i> Reflexivity, description of theoretical framework and analysis, two interviews<br><i>Negative:</i> Small sample, nursing home context details         |
| Johansson et al., 2014 (Sweden)<br>RQ: 2      | Narrative interviews<br>Descriptive with content analysis<br>6 care homes | Family<br>10 | Aspects facilitating and hindering the care-relinquishing process                            | Family wish to remain connected despite separation, negative expectations of care and lack of information hindered relinquishment while being recognised as partners in care after placement facilitated relinquishment   | MMAT: ****<br><i>Positive:</i> Methodological reflection and assumptions, circular and consensus-based analysis<br><i>Negative:</i> Small sample, sample site profile unclear        |
| Lau et al., 2008 (Taiwan)<br>RQ: 1 and 2      | Interviews<br>Grounded theory<br>1 care home                              | Family<br>11 | Family-staff process used for collaborative relationship development                         | Families applied institutional social penetration (constant interaction between self-disclosure, evaluation of care and penetration strategies) to develop family-staff relationships   | MMAT: ****<br><i>Positive:</i> Credibility strategies, description of data collection and analysis<br><i>Negative:</i> Small sample, site description, partial reflexivity described |

(Continued)

Table 2. (Continued.)

| Authors   | Method, approach and setting   | N  | Key domain and time-points (single unless stated)  | Key results  | Quality rating and comments   |
|---|--|--|--|--|---|
| Legault and Ducharme, 2009 (Canada)<br>RQ: 2        | Semi-structured interviews<br>Grounded theory<br>3 long-term care facilities                               | Family<br>14 daughters                         | Change in advocacy role  | Advocacy role evolved over time based on three related processes; development of trust, integration into the setting and evaluation of care quality  | MMAT: ****<br><i>Positive:</i> Reflexivity, bias prevention, reporting<br><i>Negative:</i> Missing sample group   |
| Lethin <i>et al.</i> , 2016 (Sweden)<br>RQ: 1 and 2 | Focus group interviews<br>Descriptive with content analysis<br>At least 4 care homes from 4 municipalities | Family<br>23<br>Residents<br>12 (in care home) | Family experiences of formal care when caring for a person living with dementia, through the stages of the disease | Families placed importance on collaboration and remaining involved, being encouraged to have influence, staff responsiveness for trust and security development. Adequate communication with staff key prerequisite to being involved  | MMAT: ***<br><i>Positive:</i> Independent coding, inter-rater reliability and consensus used, bias and reflexivity considered, limitation reporting<br><i>Negative:</i> Small sample, low representation of varied groups, no standardisation due to methods, retrospective data cases, author philosophical stance unknown |
| Majerovitz <i>et al.</i> , 2009 (USA)<br>RQ: 2      | Interviews, focus groups, survey<br>Grounded theory<br>32 care homes                                       | Family<br>103<br>Staff<br>446                  | Staff-family communication and co-operative partnership  | Multiple hindrance factors including poor staff-family communication, inadequate information, supervisors being unwilling to hear negative feedback, understaffing or erratic staffing; family guilt, hypervigilance, dissatisfaction with care and unrealistic expectations | MMAT: ***<br><i>Positive:</i> Description of research questions and included studies<br><i>Negative:</i> Method description, credibility, sample selection  |

(Continued)

Table 2. (Continued.)

| Authors   | Method, approach and setting   | N            | Key domain and time-points (single unless stated)   | Key results   | Quality rating and comments   |
|---|--|--------------|---|---|---|
| Mariani <i>et al.</i> , 2017 (Italy and the Netherlands)<br>RQ: 1 and 2 | Focus group interviews<br>Descriptive with content analysis<br>2 care homes (1 in Italy; 1 in the Netherlands) | Staff<br>19  | Barriers, facilitators and influencing factors to the implementation of a SDM framework for care planning of which involving family was a central aim | Training using role play found to be useful for staff learning how to involve residents and their family care-givers in an optimal way. Improvements were found in co-operation with families and resident care records after SDM. Multi-disciplinary working and communication skills cited as key to enabling FI, as were family compliance-related factors; closeness of family and resident, usual involvement with care tasks, family perceptions about need for SDM | MMAT: ****<br><i>Positive:</i> Interview guide, multi-country, inter-rater agreement and consensus, group difference considered, well-reported analysis results and participant quotes<br><i>Negative:</i> Small sample size, difference in dementia severity by location, 1 setting per location, different languages used |
| Seiger Cronfalk <i>et al.</i> , 2017 (Sweden)<br>RQ: 1 and 2            | Narrative and semi-structured interviews<br>Descriptive with content analysis<br>1 care home                   | Family<br>10 | Family own life experiences before and after relative placement   | Most families expressed responsibility for the resident, visited at least once per week, increased their assistance with hands-on care as residents' dementia progressed and reported feeling welcome. Other families reported negative experiences and being ill-treated   | MMAT **<br><i>Positive:</i> Examples of interview questions provided, analytical approach referenced, participant quotes included<br><i>Negative:</i> Small sample, 1 home, inconsistent number of interviewers, missing family-resident and analysis details (who), author philosophical stance unknown                    |

(Continued)

Table 2. (Continued.)

| Authors   | Method, approach and setting   | N                              | Key domain and time-points (single unless stated)   | Key results  | Quality rating and comments   |
|---|--|--------------------------------|---|--|---|
| Stirling <i>et al.</i> , 2014 (Australia)<br>RQ: 2  | Interviews, focus and action groups<br>Dementia and Dying: discussion tool<br>4 care homes | Family<br>11                   | Facilitation of staff–family communication about palliative care  | Families and staff reported the tool promoted a different type of communication where families were engaged, confidence in talking about dementia trajectory and palliative care was improved and family–staff relationships were enhanced | MMAT: ***<br><i>Positive:</i> Description of tool development, stakeholder review<br><i>Negative:</i> Small sample, no result verification, researcher influence unclear  |
| Strang <i>et al.</i> , 2006 (Canada)<br>RQ: 1 and 2 | Interviews<br>Descriptive<br>Facility type unknown   | Family<br>15                   | Family members’ experience after relative placement<br>Final point ≤ 3 months after placement   | Family relationships with resident did not change after placement, families engaged in numerous care tasks to maintain continuity, retain control, demonstrate commitment to others, and assuage guilt and ambivalence                     | MMAT: ***<br><i>Positive:</i> Credibility process and analysis description<br><i>Negative:</i> Reflexivity, care facility reporting   |
| Walmsley and McCormack, 2017 (Australia)<br>RQ: 1   | Video-recorded observations<br>Phenomenological with thematic analysis<br>4 care homes     | Family<br>14<br>Residents<br>5 | Relational social engagement and retained awareness in people with severe dementia during interactions with family<br>Two separate time-points at families’ convenience | Family interactions during visits resulted in retained awareness beyond assessed levels in those with severe dementia. Relational social engagement evident whether interactions were positive or negative                                 | MMAT: ***<br><i>Positive:</i> Independently audited, data separately analysed, linked to theory, researcher stance reported and bias considered<br><i>Negative:</i> Subjectivity of interpretation especially when speech of residents was limited, small sample size, care home details missing from results |

Notes: MMAT: Mixed Methods Appraisal Tool. PCC: person-centred care. RQ: research question. SDM: Shared Decision Making. UK: United Kingdom. USA: United States of America.

## Research questions

Results addressing the first two research questions are reported here.

### **Research question 1: What type of involvement do families have with care homes following placement of people living with dementia?**

FI is complex, multi-dimensional and potentially unique for each family. For example, families' reasons for moving their relatives living with dementia to a care home mentioned in the papers included aggressive behaviour, care-giver burden, need for help with end-of-life care and deteriorating relationships. Twenty-eight out of the 33 papers informed the varied and related types of FI shown in Table 4. Of the nine cross-sectional analyses, five correlational longitudinal analyses, one descriptive analysis and 13 qualitative studies, three achieved MMAT scores of \*\* or below. Findings remain included as other studies identified similar types of FI.

One study found that families perceived there to be fewer opportunities for participation in the very types of involvement they deemed to be most important: ensuring a well-cared for relative, active development of trust in staff, inclusion in decision making and being informed about care plan changes (Reid and Chappell, 2017). Similarly, in a large sample, families reported a difference between actual and wished-for involvement (Helgesen *et al.*, 2015).

While families acted as advocates and spokespeople for relatives after placement (Port *et al.*, 2005; Bramble *et al.*, 2009; Legault and Ducharme, 2009; Helgesen *et al.*, 2012, 2015), one study found families rarely participated in decision making regarding relatives' everyday care or health care (Helgesen *et al.*, 2015). Four studies found types of FI included seeking connection and collaboration with staff, preserving both the continuity of family-resident relationship and the resident's sense of self (Strang *et al.*, 2006; Bramble *et al.*, 2009; Edvardsson *et al.*, 2010; Lethin *et al.*, 2016).

Seven studies considered types of involvement alongside satisfaction and confidence in care and found contrasting results (Levy-Storms and Miller-Martinez, 2005; Gladstone *et al.*, 2006; Grabowski and Mitchell, 2009; Helgesen *et al.*, 2012; Reinhardt *et al.*, 2015; Lethin *et al.*, 2016; Toles *et al.*, 2018). While satisfaction with care was highest where families had minimal or no involvement with care homes (Grabowski and Mitchell, 2009), for other families, the more they were involved in discussions with staff, the greater their satisfaction with care (Reinhardt *et al.*, 2015) and sense of security (Lethin *et al.*, 2016). FI in the provision of personal and instrumental care prior to placement was related to lower levels of satisfaction with care, provided by the care home at admission, and this did not change over time (Levy-Storms and Miller-Martinez, 2005).

### **Visitation, frequency and level of FI**

Twelve studies explored frequency of involvement with visits as a core domain (Dobbs *et al.*, 2005; Port *et al.*, 2005; Zimmerman *et al.*, 2005; Gladstone *et al.*, 2006; Minematsu, 2006; Grabowski and Mitchell, 2009; Cohen *et al.*, 2014; Helgesen *et al.*, 2015; Reinhardt *et al.*, 2015; Livingston *et al.*, 2017; Seiger Cronfalk *et al.*, 2017; Forsund and Ytrehus, 2018). An additional study captured the level of FI in care using a multifactorial scale that included visits (Boogaard *et al.*, 2017).

**Table 3.** Mixed Methods Appraisal Tool (MMAT) scores for included studies

| Study                                       | MMAT |
|---|------|
| Quantitative studies:                       |      |
| Minematsu (2006)                            | *    |
| Dobbs <i>et al.</i> (2005) <sup>1</sup>     | ***  |
| Grabowski and Mitchell (2009)               | ***  |
| Reinhardt <i>et al.</i> (2015)              | ***  |
| Ampe <i>et al.</i> (2016)                   | **** |
| Boogaard <i>et al.</i> (2017)               | **** |
| Cohen <i>et al.</i> (2014)                  | **** |
| Helgesen <i>et al.</i> (2015)               | **** |
| Levy-Storms and Miller-Martinez (2005)      | **** |
| Livingston <i>et al.</i> (2017)             | **** |
| McCreeley <i>et al.</i> (2018)              | **** |
| Reid and Chappell (2017)                    | **** |
| Toles <i>et al.</i> (2018)                  | **** |
| Zimmerman <i>et al.</i> (2005) <sup>1</sup> | **** |
| Qualitative studies:                        |      |
| Edvardsson <i>et al.</i> (2010)             | **   |
| Seiger Cronfalk <i>et al.</i> (2017)        | **   |
| Forsund and Ytrefhus (2018)                 | ***  |
| Lethin <i>et al.</i> (2016)                 | ***  |
| Majerovitz <i>et al.</i> (2009)             | ***  |
| Stirling <i>et al.</i> (2014)               | ***  |
| Strang <i>et al.</i> (2006)                 | ***  |
| Walmsley and McCormack (2017)               | ***  |
| Caron <i>et al.</i> (2005)                  | **** |
| Gladstone <i>et al.</i> (2006)              | **** |
| Helgesen <i>et al.</i> (2012)               | **** |
| Johansson <i>et al.</i> (2014)              | **** |
| Lau <i>et al.</i> (2008)                    | **** |
| Legault and Ducharme (2009)                 | **** |
| Mariani <i>et al.</i> (2017)                | **** |
| Mixed-methods studies:                      |      |
| Carter <i>et al.</i> (2018) <sup>2</sup>    | ***  |
| Port <i>et al.</i> (2005) <sup>1</sup>      | ***  |

(Continued)

**Table 3.** (Continued.)

| Study                                     | MMAT |
|---|------|
| Bramble <i>et al.</i> (2009) <sup>3</sup> | **** |
| Bramble <i>et al.</i> (2011) <sup>3</sup> | **** |

Most papers reported or demonstrated that the majority of families remain involved with relatives following placement. In the Livingston *et al.* (2017) study with a large sample ( $N > 1,000$ ), the median number of visits to residents by a main family carer was found to be six per month. A correlational study ( $N = 90$ ) noted in their sample description that 47 per cent of families visited relatives at least once per week (Reinhardt *et al.*, 2015). Two cross-sectional studies (Dobbs *et al.*, 2005; Helgesen *et al.*, 2015) with larger samples ( $N = 400$ ;  $N = 233$ ) found the percentages of visiting families were higher: 70 and 84.1 per cent, respectively.

Four correlational studies reported that some families spend seven or more hours per week or over ten visits per month with residents (Zimmerman *et al.*, 2005; Minematsu, 2006; Grabowski and Mitchell, 2009; Cohen *et al.*, 2014). Similarly, participant characteristics described in two qualitative studies (Seiger Cronfalk *et al.*, 2017; Forsund and Ytrehus, 2018) noted a minimum of weekly visits and an average number of visits as just over three per week (range of one to seven), respectively.

When non-visit-based FI with care homes is considered, overall FI may be higher. A quantitative study found that 12 months after resident placement, 23 per cent of families had more contact with their relative and the average weekly number of family visits had increased to just over two and a half times per week (Gladstone *et al.*, 2006). One study compared visits by type of residential facility and found there to be no difference in frequency of visitation (Port *et al.*, 2005).

Boogaard *et al.* (2017) explored the level of FI in care ( $N = 214$ ) across eight factors including visits. They found an average score of 21 out of a possible 40, however, a positive association between FI and overall trust in staff was not sustained once analyses accounted for clustering in nursing homes. Another study of over 18,000 long-stay residents living with dementia revealed that only 16 per cent had a family member or representative involved in at least one planning assessment over the course of one year. Over half of the residents with severe cognitive impairment had no representation in that same period (McCreedy *et al.*, 2018).

### *Themes and country representation*

During analysis of the included papers, types of FI were grouped for similarity and relatedness. Figure 2 shows seven connected yet distinct themes that stood out amongst the groups: *Visit and contact*; *Participate in care delivery (core needs)*; *Advocate and guardianship*; *Supervise, influence and direct care*; *Monitor care*; *Evaluate quality of care*; and *Collaborate and develop active partnership*. FI themes indicated separate parts of a family- and resident-centred care process, that takes place from the time of a resident's placement to the end of their life. There appeared

**Table 4.** Types of family involvement after placement of a relative living with dementia

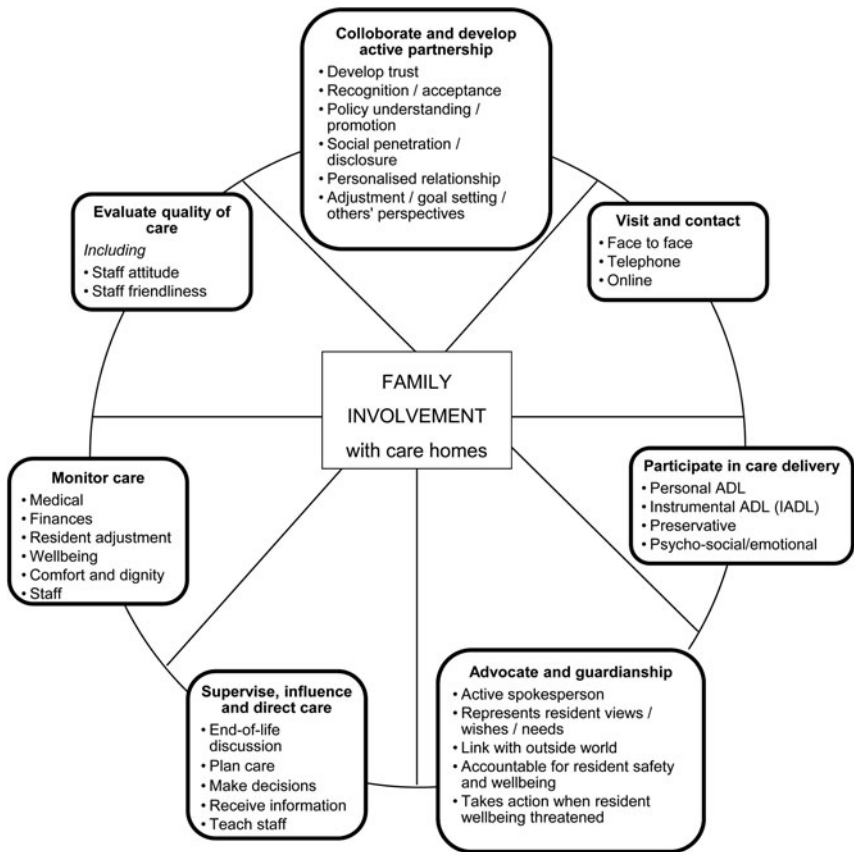
| Activities undertaken (potential roles/purpose) with care homes   |
|---|
| <p><b>Visit and contact</b> (Boogaard, Cohen; Dobbs; Forsund; Gladstone; Grabowski; Helgesen; Helgesen<sup>1</sup>; Livingston; Minematsu; Port; Reinhardt; Seiger Cronfalk; Walmsley; Zimmerman)</p> <p><b>Personal (activities of daily living; ADL) support</b> (Gladstone; Levy; Port; Seiger Cronfalk)</p> <p><b>Instrumental (IADL) support</b> (Lau; Levy; Gladstone; Port; Seiger Cronfalk)</p> <p><b>Preservative support</b> (Edvardsson; Forsund; Gladstone; Helgesen; Lau; Port):</p> <ul style="list-style-type: none"> <li>• <i>Kinship, maintain relationship/life, connection with past (Edvardsson; Forsund; Lau; Port)</i></li> <li>• <i>Provide link to outside world (Helgesen)</i></li> </ul> <p><b>Psycho-social/emotional support</b> (Dobbs; Gladstone; Port):</p> <ul style="list-style-type: none"> <li>• <i>Participate in social activities to encourage resident participation (Dobbs)</i></li> <li>• <i>Assess activities (Dobbs)</i></li> </ul> <p><b>Collaborate and actively develop family–staff partnerships</b> (Caron; Edvardsson; Lau; Lethin; Reid):</p> <ul style="list-style-type: none"> <li>• <i>Develop trust (Edvardsson; Lethin; Reid), pre-existing or blind (Caron)</i></li> <li>• <i>Understand and promote care home policies</i></li> <li>• <i>Recognise and accept care home (Lau)</i></li> <li>• <i>Make emotional adjustments – identify goals and others’ perspectives (Lau)</i></li> <li>• <i>Achieve institutional social penetration (Lau):</i></li> <li>• <i>With self-disclosure (Lau)</i></li> <li>• <i>Seek personalised relationship with staff (Caron)</i></li> </ul> <p><b>Advocate</b> (Bramble; Helgesen; Helgesen<sup>1</sup>; Legault; Port)</p> <p><b>Be guardian</b> (Grabowski; Helgesen; Lethin)</p> <p><b>Supervise, influence and direct care</b> (Carter; Edvardsson; Reid; Reinhardt; Port):</p> <ul style="list-style-type: none"> <li>• <i>Participate in end-of-life discussions (Ampe; Carter; Reinhardt)</i></li> <li>• <i>Plan care (Ampe; Lethin; McCreedy; Port)</i></li> <li>• <i>Make decisions (Carter; Helgesen<sup>1</sup>, Mariani; Port; Reid; Toles)</i></li> <li>• <i>Receive information about care changes (Carter; Reid)</i></li> <li>• <i>Teach staff/be a resource:</i></li> <li>• <i>Share unique knowledge of resident with staff (Edvardsson, Lethin)</i></li> </ul> <p><b>Monitor quality of care</b> (Bramble; Gladstone; Grabowski; Helgesen; Port; Reid; Seiger Cronfalk):</p> <ul style="list-style-type: none"> <li>• <i>Medical (Port) and physical care (Bramble)</i></li> <li>• <i>Finances (Port)</i></li> <li>• <i>Resident adjustment (Gladstone), wellbeing (Port; Reid), comfort and dignity (Helgesen)</i></li> <li>• <i>Staff (Gladstone; Seiger Cronfalk)</i></li> </ul> <p><b>Evaluate quality of care</b> (Bramble; Lau; Legault; Strang):</p> <ul style="list-style-type: none"> <li>• <i>Attitude of staff and friendliness (Bramble)</i></li> </ul> |

Notes: Italics refer to a ‘new’ type or sub-type of involvement, i.e. a type that was not distinguished (‘known’) in the paper by Gaugler (2005). Apart from ‘new’ types of family involvement, sub-types within personal, instrumental, preservative and psycho-social support are well known and have not been displayed to save space. References to Bramble refer to Bramble et al. (2009) and Helgesen<sup>1</sup> refers to Helgesen et al. (2015) (authors involved in multiple papers in this review).

to be a sequence to some of the themes, for example, *Visit–Advocate–Supervise–Monitor–Evaluate*. However, the process is more accurately non-linear; themes of FI types are completed in parallel and in an iterative manner.

Country differences across themes of FI were compared and are displayed in Table 5. Papers based in Australia, Canada, Sweden and the USA highlighted six or more of all seven themes, while papers from Israel, Italy, Japan and the Netherlands highlighted one (and a different) theme only. The themes with 50 per cent or more of the possible country representation included *Visit and contact*, *Participate in care delivery (core needs)*, *Supervise, influence and direct care* and *Collaborate and develop active partnership*.





**Figure 2.** Non-linear process and related themes in types of family involvement following placement of a relative living with dementia in a care home.

*Person- and family-centred care*

Table 6 shows the proposed assignment of identified FI type to PCC and FCC core principles and concepts; NICE (2018) and IPFCC definitions were employed. Overall, FI types appeared to fit well with PCC and FCC. The majority of FI types matched well to PCC *Carer*, a statement that refers to *the importance of taking account of the needs of carers including family*. However, this result was expected. For consistency, authors treated the statement similarly to the distinguished PCC principles and assigned FI types on this basis. This principle proved to be a *catch all* as many FI types were assigned to it. Likewise, FI activity of *collaborate and actively develop family-centred partnerships* was not easily assigned to PCC principles, however, it was explicitly addressed in FCC concepts.

Of 33 identified types of FI, over 30 per cent matched to the PCC *Human value* principle. *Individuality* and *Person’s perspective* attracted under 20 per cent of the possible FI types. Most were assigned to FCC concepts of *Participation* (64%) and *Dignity and respect* (39%). In contrast, *Information sharing* attracted only 5 per cent of possible types of FI.

**Table 5.** Themes of family involvement (FI) activities by country and following placement of a relative living with dementia in a care home

| Types of FI by theme                       | Countries represented in included papers (2005–2018) relevant to types of FI |         |        |        |       |       |             |        |        |        |    |     |
|--|--|---------|--------|--------|-------|-------|-------------|--------|--------|--------|----|-----|
|  | Australia  | Belgium | Canada | Israel | Italy | Japan | Netherlands | Norway | Sweden | Taiwan | UK | USA |
| Visit and contact                          | X  |         | X      | X      |       | X     |             | X      | X      |        | X  | X   |
| Participate in care delivery (core needs)  | X  |         | X      |        |       |       |             | X      | X      | X      |    | X   |
| Advocate and guardianship                  | X  |         | X      |        |       |       |             | X      | X      |        |    | X   |
| Monitor care                               | X  |         | X      |        |       |       |             | X      | X      |        |    | X   |
| Evaluate quality of care                   | X  |         | X      |        |       |       |             |        |        | X      |    |     |
| Supervise, influence and direct care       | X  | X       |        |        | X     |       | X           | X      | X      |        | X  | X   |
| Collaborate and develop active partnership | X  | X       | X      |        |       |       |             |        | X      | X      |    | X   |

Notes: UK: United Kingdom. USA: United States of America.

**Table 6.** Types of family involvement in care homes after placement of a relative living with dementia assigned to person-centred care (PCC) and family-centred care (FCC) principles

| Activities undertaken at/with care home (potential roles/purpose)    | PCC <sup>1</sup> |               |                      |                         |                     | FCC <sup>2</sup>    |                     |               |               |
|--|------------------|---------------|----------------------|-------------------------|---------------------|---------------------|---------------------|---------------|---------------|
|  | Human value      | Individuality | Person's perspective | Social and relationship | Carers <sup>3</sup> | Dignity and respect | Information sharing | Participation | Collaboration |
| Visit and contact  | ✓                |               |                      | ✓                       |                     | ✓                   |                     | ✓             |               |
| Personal (activities of daily living; ADL) support                   |                  |               |                      |                         |                     | ✓                   |                     | ✓             |               |
| Instrumental (IADL) support  | ✓                |               |                      |                         |                     | ✓                   |                     | ✓             |               |
| Preservative support:  | ✓                |               |                      | ✓                       | ✓                   | ✓                   |                     | ✓             |               |
| Kinship, maintain relationship/life, connection with past            | ✓                |               |                      | ✓                       | ✓                   | ✓                   |                     | ✓             |               |
| Provide link to outside world  | ✓                | ✓             |                      | ✓                       |                     |                     |                     | ✓             |               |
| Psycho-social/emotional support:                                     |                  |               |                      | ✓                       |                     |                     |                     | ✓             |               |
| Participate in social activities to encourage resident participation |                  | ✓             |                      | ✓                       |                     |                     |                     | ✓             |               |
| Assess activities  |                  | ✓             |                      |                         | ✓                   | ✓                   |                     |               | ✓             |
| Collaborate and actively develop family-staff partnerships:          |                  |               |                      |                         | ✓                   |                     |                     | ✓             | ✓             |
| Develop trust (pre-existing or blind)                                |                  |               |                      |                         | ✓                   |                     |                     |               |               |
| Understand and promote care home policies                            |                  |               |                      |                         |                     |                     |                     |               | ✓             |
| Recognise and accept care home                                       |                  |               |                      |                         |                     |                     |                     |               | ✓             |
|  |                  |               | ✓                    |                         | ✓                   |                     |                     |               | ✓             |

|  |   |   |   |   |   |   |
|--|---|---|---|---|---|---|
| Make emotional adjustments – identify goals and others’ perspectives |   |   |   |   |   |   |
| Achieve institutional social penetration:                            |   |   | ✓ |   |   | ✓ |
| With self-disclosure   |   |   | ✓ |   |   |   |
| Seek personalised relationship with staff                            |   |   | ✓ | ✓ |   | ✓ |
| Advocate   |   | ✓ |   | ✓ |   |   |
| Be guardian  | ✓ |   | ✓ |   | ✓ |   |
| Supervise, influence and direct care: <sup>4</sup>                   |   |   | ✓ |   | ✓ | ✓ |
| Participate in end-of-life discussions                               | ✓ | ✓ | ✓ |   | ✓ |   |
| Plan care  |   | ✓ | ✓ | ✓ |   |   |
| Make decisions   |   |   | ✓ |   | ✓ |   |
| Receive information about care changes                               |   |   | ✓ |   | ✓ |   |
| Teach staff/be a resource  |   | ✓ |   | ✓ | ✓ | ✓ |
| Share unique knowledge of resident with staff                        |   | ✓ | ✓ |   | ✓ |   |
| Monitor quality of care:   | ✓ |   | ✓ |   | ✓ | ✓ |
| Medical and physical care  | ✓ |   |   |   | ✓ |   |
| Finances   | ✓ |   |   |   | ✓ |   |

(Continued)

**Table 6.** (Continued.)

| Activities undertaken at/with care home (potential roles/purpose) | PCC <sup>1</sup> |               |                      |                         |                     | FCC <sup>2</sup>    |                     |               |               |
|---|------------------|---------------|----------------------|-------------------------|---------------------|---------------------|---------------------|---------------|---------------|
|   | Human value      | Individuality | Person's perspective | Social and relationship | Carers <sup>3</sup> | Dignity and respect | Information sharing | Participation | Collaboration |
| Resident adjustment, wellbeing                                    |                  | ✓             | ✓                    | ✓                       |                     | ✓                   |                     | ✓             |               |
| Staff   |                  |               |                      |                         | ✓                   |                     |                     | ✓             |               |
| Evaluate quality of care:   | ✓                |               |                      |                         | ✓                   |                     | ✓                   | ✓             | ✓             |
| Attitude of staff and friendliness                                | ✓                |               |                      |                         |                     | ✓                   | ✓                   | ✓             |               |

Notes: 1. PCC principles in National Institute for Health and Care Excellence (NICE, 2018) guideline. 2. FCC concepts by the Institute for Patient and Family Centred Care (available at <https://www.ipfcc.org/about/pfcc.html>, November 2020). 3. Refers to family and friends or paid care workers. 4. Assumes family involvement type encompassed by NICE PCC statement (not a principle) of the importance of taking account of the needs of carers including family.

### Research question 2: Which factors influence FI with care homes?

Factors that influence FI are multiple, varied and interwoven across the agents involved; the care home, its staff, the resident and the family (see Table 7). Influences do not occur in isolation. They contribute to the dynamic nature of FI and the unique inter-family and intra-family preferences of and about involvement. Twenty-five of the 33 papers in this review considered factors that influence involvement and a slight majority highlighted at least one factor that either aided involvement or resulted in increased contact or visits. Of the 15 qualitative and ten quantitative studies, one study achieved a MMAT score of \* so was excluded from these results. In another study with a score of \*\* a restricted set of findings are reported here as the results section of the paper appeared incomplete; when additional results (without supporting participant quotes) were reported in the discussion these were excluded from consideration in our review.

Alongside family evaluation of care, the important factors influencing FI found across nine studies were: family trust in staff, family desire for integration into the care team and their wish for development of close, personal, family–staff relationships (Caron *et al.*, 2005; Port *et al.*, 2005; Gladstone *et al.*, 2006; Lau *et al.*, 2008; Legault and Ducharme, 2009; Majerovitz *et al.*, 2009; Helgesen *et al.*, 2012; Johansson *et al.*, 2014; Lethin *et al.*, 2016; Reid and Chappell, 2017).

Trust facilitated contact although it both enabled and excused family participation in decision making (Caron *et al.*, 2005; Boogaard *et al.*, 2017; Reid and Chappell, 2017). A lack of trust and a care evaluation of ‘poor’ were linked with increased supervision and advocacy (Strang *et al.*, 2006; Legault and Ducharme, 2009; Helgesen *et al.*, 2012) and hindered positive family–staff relationships (Lau *et al.*, 2008; Majerovitz *et al.*, 2009). Similarly, when exploring resident and family care-giver involvement in a specific type of FI, that of shared decision making, Mariani *et al.* (2017) found a circuitous influential factor. The degree of families’ usual involvement in relatives’ lives and in their care facilitated further FI in shared decision making.

Desire for both participation and recognition as a care partner increased involvement (Caron *et al.*, 2005; Port *et al.*, 2005; Johansson *et al.*, 2014), while poor, inadequate, unstructured family–staff communication inhibited participation (Bramble *et al.*, 2009; Stirling *et al.*, 2014; Lethin *et al.*, 2016). Changes in resident adjustment and mood could both motivate involvement or result in fewer visits (Gladstone *et al.*, 2006; Helgesen *et al.*, 2012), although when specifically explored, higher agitation was not associated with family visits (Livingston *et al.*, 2017).

Involvement in resident personal care and monitoring of staff reduced as confidence in care delivery increased. However, as a resident’s cognitive impairment, physical symptoms and BPSD deteriorated, family visits and the likelihood of participation in care planning increased (Gladstone *et al.*, 2006; Helgesen *et al.*, 2012; McCreedy *et al.*, 2018). In contrast, other studies found no difference in visit frequency as a function of dementia severity (Cohen *et al.*, 2014) or length of placement (Gladstone *et al.*, 2006; Legault and Ducharme, 2009).

Family care-giver characteristics such as age, gender and education level, and resident characteristics such as ethnicity and payment method (state or other/private) appeared to be important participation factors. However, intergenerational

dynamics and factors influencing grandchild involvement seemed surprisingly absent. Helgesen *et al.* (2015) found: perceptions of the importance of FI is varied based on education level, relevant knowledge held about residents is higher amongst females and elder family members appear to attract more offers of support from staff. McCreedy *et al.* (2018) found associations between family participation and the following: residents being of black heritage, requiring an interpreter to communicate, level of ADL dependencies, displayed behaviours (e.g. aggression) and other health factors.

However, these factors are not all included in Table 7 as whether they enable or prohibit FI and increase or decrease visits is still unknown and contrasting results are evident. For instance, given trust and communication are known to be key in FI, studies found no significant link between FI and education and trust in staff (Boogaard *et al.*, 2017) or education and quality of communication (Toles *et al.*, 2018). An association between ethnicity and lower trust in health professionals and a link between involvement in care and overall trust, were found (Boogaard *et al.*, 2017).

FI was facilitated when care home policies, practice and physical environment overtly considered family participation. Higher social worker ratios were linked to higher family participation though care home characteristics (including quality ratings) did not explain the majority of variance in FI between care homes (McCreedy *et al.*, 2018). When staff were encouraged to: offer opportunities to families to be involved, foster personalised, open relationships and raised (and were trained to raise) difficult topics such as end-of-life goals, family care-givers reported being able to engage and access support (Port *et al.*, 2005; Gladstone *et al.*, 2006; Bramble *et al.*, 2009; Majerovitz *et al.*, 2009; Ampe *et al.*, 2016; Reid and Chappell, 2017; Carter *et al.*, 2018; Forsund and Ytrehus, 2018).

Toles *et al.* (2018) found families rated quality of communication as poor when important end-of-life topics were omitted from communication. However, as Ampe *et al.* (2016) discovered, when comparing policy to practice, staff tend to only use baseline skills when involving families; approximately half of the staff–family conversations about advanced care planning in their study were not substantive. Mariani *et al.* (2017) found both over- and underregulation, and a lack of funding, impacted implementation of a decision-making framework aimed at improving family (and resident) participation.

## Summary

A wide array of types of FI and factors that influence FI following placement of a relative living with dementia have been identified. When grouped, seven themes forming part of a non-linear process stood out. Cross-country comparisons showed both similarities and differences. Identified FI types fit neatly with PCC and FCC principles, however, some matches are less convincing than others. There is a complex, multi-dimensional and evolving interplay across: family-assigned roles, the activities in which families participate, the nature of family and staff participation preferences, and the interactions between the care home (environment, culture, policies and systems) and the three parties (families, residents and staff).

## Discussion

### *What do we know now that we did not know in 2005?*

FI activities are broader in range than originally identified and differences between types are now distinct and better understood. New types and sub-types of involvement have been highlighted in Table 4 alongside the 11 overarching types of non-dementia-specific FI that were understood in 2005. Emphasis has moved beyond personal, instrumental, preservative and socio-emotional care activities (Gladstone *et al.*, 2006).

Seven themes of FI activities shown in Figure 2 have been proposed along with a non-linear process of FI undertaken with varying theme emphases throughout the duration of a resident's placement. Being an advocate, spokesperson and guardian were repeatedly identified as important involvement activities and roles (see Table 4); a contrast to 2005 when advocacy was not a prominent feature (MacDonald, 2005). This change concurred with recent literature (Graneheim *et al.*, 2014; Petriwskyj *et al.*, 2014).

Now, a distinction is made between *active* advocate involvement and the more passive visitor involvement (Helgesen *et al.*, 2012). The discrete themes of FI types also reflect this, *e.g.* *Participate in care delivery (core needs)* is distinct from *Supervise, influence and direct care* or *Monitor care*, both of which require proactive forms of engagement.

Within a new landscape of care partnerships, positive family–staff relationships are no longer enough; families seek personalised, meaningful relationships with staff and recognition of their role as a care partner (Caron *et al.*, 2005; Aveyard and Davies, 2006; Lau *et al.*, 2008; Bramble *et al.*, 2009). Consistent with other reviews (Gaugler, 2005; Petriwskyj *et al.*, 2014), the majority of families wish to remain involved and become more involved with care homes following placement of their relative.

It is likely that the expansion in types of FI are driven by a number of varied factors. The increased publicity about the inner workings of residential institutions and media spotlight on examples of negligence or abuse has led to families' increased awareness of what can go wrong when they are not involved or do not retain a level of supervision within care homes. Similarly, the CQC (2015), NICE (2018) and recommended care home guidelines place emphasis on encouraging FI. In cultures where the individual is central, society norms mean fewer intergenerational families live together for support, however, value is still placed on individuals' rights, dignity, identity and perspective regardless of their health status. Therefore, families may wish to uphold these norms through advocacy, protect their own mental health as they and their relative adjust, and it is likely they also wish to model involvement with care homes for younger family members in order to safeguard their own care in the future. Similarly, families recognise their rights to involvement and increasingly expect to be accommodated by care home policy and staff.

### *Influences on FI*

This review confirmed that the array of factors already known to influence FI with care homes also pertain to FI following placement of a relative living with dementia.



However, additional variables that prohibit or provide motivation for involvement were also identified. In line with another review (Petriwskyj *et al.*, 2014), understaffing and unhelpful staff working patterns hindered participation (Bramble *et al.*, 2009; Majerovitz *et al.*, 2009) and involvement in a shared decision-making framework, as did competing demands on families (Gladstone *et al.*, 2006). Akin to recent literature (Graneheim *et al.*, 2014; Petriwskyj *et al.*, 2014), quality of staff–family relationships (Bramble *et al.*, 2009), staff offers of FI opportunities and assistance (Reid and Chappell, 2017), as well as families’ perception that they are recognised as a care partner (Johansson *et al.*, 2014) with unique knowledge of the resident, all facilitate involvement.

In a recent study conducted by Lao *et al.* (2019), Chinese residents (though not specific to dementia) highlighted influencing factors similar to those found in this review, including family commitments, age, financial concerns, family–resident relationship and limited visiting hours. Importantly, and in contrast to Etkind *et al.* (2018), only 50 per cent of families with relatives living with dementia consider their involvement to be crucial for resident wellbeing after placement (Helgesen *et al.*, 2015) and this perception alone may be a significant contributing factor to why some families engage less or do not get involved with care homes.

### **PCC and FCC**

While few gaps were found between FI types and PCC/FCC frameworks, FI types were assigned applying an assumption that core types of involvement (that may be perceived as more threatening or less welcome in partnership) such as *monitoring, supervision and evaluation of care* were included in overarching PCC philosophy about family carers. If this assumption is inappropriate then important types of FI are not yet clearly and fully represented by current PCC principles.

Why might that be? It is possible that some families do not value PCC or the same principles and this could be related to cultural or family dynamic concerns. Alternatively, families may not have been encouraged to learn about and engage in PCC/FCC-based activities that are known to be effective, so are relying solely on their own ideas about how to remain involved. Further research to redefine and enhance PCC/FCC is required.

Why are PCC/FCC principles of *Individuality, Person’s perspective* and *Information sharing* not represented by the types of FI that the literature shows families with residents living with dementia in care homes undertake? Could it be that pragmatic application of care home policies are yet to, or inconsistently, reflect these principles? After all, implementing PCC into daily practice is challenging (Vernooij-Dassen and Moniz-Cook, 2016); or possibly more likely, few interventions to target these principles have been adopted and, as Fazio *et al.* (2018) point out, more research is required.

When a patient- and family-centred care approach was used, expressly where contact with family and family visits were encouraged, opportunities for FI and assistance was offered and family-oriented policies were applied, a positive impact on FI ensued; FI was facilitated and stimulated. Without a FCC approach, FI was prevented and discouraged (for paper references, see the first row of Table 7). Interestingly, care home use of FCC approaches did not necessarily mean families visited or increased

their contact; studies showed contrasting results. Therefore, when care homes adopt and practise PCC with a focused FCC component, families may fulfil some of the resource requirements that care homes anticipate needing, now and for the future, yet employ a 'light touch', one that incorporates staff needs and respects staff time constraints. In other words, families and staff would operate in a manner of personalised partnership, the very approach that families seek.

### Strengths and limitations

Three databases and three researchers were used for the search. Extensive hand searches were completed to ensure search strategy bias was minimised. Four researchers and a consensus approach were used for paper appraisal. Five of the 50 papers included in reviews used for comparison matched our included studies. To limit reporting bias, findings that corroborate and contrast in evidence to our findings have been described when alternative papers within the reviews were cited.

The MMAT (Pluye *et al.*, 2011) has accrued positive evaluation and evidence of content validity and reliability (Crowe and Sheppard, 2011; Pace *et al.*, 2012). It has been used worldwide for at least 50 reviews. As further improvements are recommended (Souto *et al.*, 2015), caution was exercised by selecting 25 papers with studies of various designs to be appraised with the Kmet *et al.* (2004) appraisal tools. No obvious differences in appraisal between the two tools were apparent; a paper with a low Kmet *et al.* (2004) score was also found to have a low MMAT rating.

Most studies investigated a single specific topic of participation or included involvement measures and did not directly explore involvement types or influences. Therefore, in addition to care-giver stressors that are not the focus of this review, the identified types of and influences on involvement, while numerous, may be incomplete. However, this is the only known systematic review to consider types and influences of FI exclusively in relation to dementia, therefore authors have confidence that the tables displayed are useful and comprehensive.

### Implications for clinical practice

It was important to explore types of FI in order to establish if the activities that families are involved in with care homes do in fact reflect the PCC and FCC principles espoused as gold standard. Similarly, to build family profiles of involvement and ensure each family is supported by care homes in a manner conducive to their circumstances, it was important to investigate which factors influence FI and the nature of that influence. This research topic also allowed for an insight into whether a PCC approach created a positive or negative impact on FI.

Staff and families supporting a resident living with dementia can now be confident there is a good fit of family activities to PCC and FCC principles and that employment of family-centric principles within PCC positively influence FI. Exploring types of FI was useful to distinguish seven themes of participation activities. [Figure 2](#) of themes and [Table 7](#) of influencing factors form a framework for staff–resident–family discussion and agreement. This framework reaches well beyond family decisions about medical care and extends to family influence on policy and interventions. Care homes should not be surprised when families seek

engagement in macro-level activities, and when care homes need resources for care quality improvement projects families are a likely source of willing contributors.

Family roles and involvement are often dynamic and ambiguous (Graneheim *et al.*, 2014; Petriwskyj *et al.*, 2014). Expectations for involvement differ for each family (Caron *et al.*, 2005; Reid and Chappell, 2017), adding more complexity to FI after relative placement. Positive staff–family partnerships are likely if, at the outset of placement, staff enquire about family expectations, hopes for involvement and provide information about how FI is promoted within the care home. This approach, ideally underpinned by an enhanced (well-defined and fully applied) FCC framework, will help both families and staff to build an individualised family profile of involvement that can evolve over time, avoid ambiguities about roles and types of involvement each party will participate in, learn about the factors that immediately influence a specific family's involvement and model a collaborative, transparent relationship.

The commonly used description of FI (Gaugler, 2005; Reid *et al.*, 2007) could be updated. FI may be more accurately described as a multi-dimensional construct that can entail visiting, advocacy, supervising, monitoring and evaluating care, development of care partnerships and foundation care (personal, instrumental, preservative and psycho-social). This description better reflects the range and types of involvement that are important to families.

Definitions of PCC are not yet optimally fit for purpose and could benefit from being more explicit. Future guidelines for PCC in dementia should state FCC characteristics or reconcile FCC and PCC components in a consistent and clear manner. At the research, policy and practical application levels, stakeholders may interpret the meaning of principles differently. For example, FCC *Participation* and *Collaboration* may be conflated or operationalised differently leading to incomparable and inconsistent outcome recording.

FI types *Evaluation*, *Supervision* and *Monitoring of care home service and staff* may be encompassed by the overarching PCC point, *The importance of taking into account the needs of carers, supporting and enhancing carer input*. Alternatively, one improvement proposed is to acknowledge and embrace openly these FI types within the descriptions of PCC and FCC principles as they are a fundamental part of partnership. New principle descriptions may decrease ambiguities, clarify expectations, and ultimately improve communication and quality of care.

## Future research

UK-, wider European-, Asian- and southern hemisphere-based research in FI with care homes, specific to dementia, remains underrepresented. Attitude to long-term care and care culture differs across localities (van der Steen, 2012; Killest *et al.*, 2016; Mariani *et al.*, 2017; Ludecke *et al.*, 2018) and the studies in this review did not represent a wide enough range of cultures to establish cultural and regional nuances in types of FI and factors influencing FI. Instead, hints of commonalities and differences were apparent and warrant further investigation.

For example, pre-existing and blind trust by some families towards care homes reported by a Canadian study and families' active recognition and acceptance of care homes raised in a Taiwanese study, appear to be similar. In contrast, a

**Table 7.** Agents and factors that influence family involvement (FI) with care homes following placement of a relative with dementia

| Agent (care home/staff or resident or family) and influential factor  | How factor influences family involvement and paper references   |  |   |   |   |
|---|---|--|---|---|---|
|   | Overall   |  | On visits and contact   |   |   |
|   | Assists or stimulates   | Prevents or discourages  | Increases   | Decreases                                     | No influence                                    |
| Care home/staff:  |   |  |   |   |   |
| Family-oriented policies; encouraged contact with families and family visits, FI opportunities and assistance offered | Carter, Gladstone, Mariani, Reid, Port (e.g. forums, organisational openness, shared decision making) | Bramble (e.g. when not offered)  | Seiger Cronfalk (increased monitoring during organisation change) | Gladstone (e.g. when FI encouraged)           |   |
| Staff levels, work patterns, inter-staff communication  | Mariani (team collaboration)  | Bramble, Majerovitz, Mariani (e.g. workload, understaffing)  |   |   |   |
| Lack of funding and regulations   | Mariani (when regulated)  | Mariani (over- or underregulated, lack of funds)   |   |   |   |
| Staff communication with families (frequency, structure, type, content e.g. difficult topics)                         | Port, Majerovitz, Bramble Stirling (e.g. meeting regime)  | Caron, Bramble, Stirling, Majerovitz (e.g. if limited)<br>Carter (when end of life not talked about)                         | Lethin (inadequate communication)                                 |   |   |
| Type/size of care home, physical environment, geographical location and country culture                               | Forsund (private spaces assist relationships)   | Forsund (community spaces assist security, inhibit private interaction with partner)<br>Mariani (Italian motivation factors) |   | Port (e.g. when specialist dementia services) | Port (e.g. of facility type on visit frequency) |

(Continued)

Table 7. (Continued.)

| Agent (care home/staff or resident or family) and influential factor | How factor influences family involvement and paper references        |  |                                   |   |   |
|--|--|--|-----------------------------------|---|---|
|  | Overall  |  | On visits and contact             |   |   |
|  | Assists or stimulates  | Prevents or discourages  | Increases                         | Decreases   | No influence  |
| Quality of relationship with family                                  | Caron, Johansson, Bramble, Legault (e.g. if personalised)            | Carter, Majerovitz (e.g. conflict or if staff unwilling to hear negative feedback) |                                   |   |   |
| Resident:  |  |  |                                   |   |   |
| Length of placement  |  |  |                                   |   | Gladstone, Legault  |
| Increase in dementia severity/symptoms <sup>1</sup>                  | Helgesen, McCreedy (e.g. participation in care planning)             | Seiger Cronfalk (e.g. family able to do less)                                      |                                   | Gladstone, Helgesen (e.g. if unresponsiveness ensues) | Cohen (e.g. on visit frequency) Helgesen <sup>2</sup> (e.g. being recognised not crucial, exception – spouse) |
| Adjustment, mood, agitation  | Helgesen   |  |                                   | Gladstone, Helgesen (e.g. if resident adapted)        | Livingston (agitation level on visit frequency)   |
| Physical and overall health  | Helgesen   |  | Gladstone (e.g. if deterioration) |   |   |
| Ability to participate in decision making                            | Helgesen <sup>2</sup>  |  |                                   |   |   |
| Family:  |  |  |                                   |   |   |
| Feeling recognised as a care partner                                 | Helgesen <sup>2</sup> , Johansson, Lethin (e.g. consulted as expert) |  |                                   |   |   |
| Perceiving self as well-liked by staff                               | Helgesen <sup>2</sup>  |  |                                   |   |   |

|  |  |   |  |
|--|--|---|--|
| Wish to participate/<br>collaborate and respect staff                            | Legault, Lethin, Bramble,<br>Helgesen (e.g. to learn<br>new skills, staff found<br>easier to converse with<br>families)                          | Majerovitz, Helgesen<br>(e.g. difficult visits)                           |  |
| Role perception  | Gladstone, Helgesen (e.g.<br>'care-giver' led to more<br>active involvement)   | Gladstone, Helgesen<br>(e.g. 'visitor' led to less<br>active involvement) |  |
| Perceived quality and<br>satisfaction with care                                  | Lau, Legault, Bramble,<br>Helgesen (e.g. good<br>evaluation led to better<br>collaboration)<br>Boogaard (linked to trust,<br>trust linked to FI) |   | Helgesen, Gladstone<br>(e.g. passive if good<br>evaluation, less<br>monitoring)  |
| Perceived opportunities for<br>involvement and existing<br>degree of involvement | Mariani, Reid  |   |  |
| Trust in staff <sup>1</sup>  | Lethin, Reid (e.g. key<br>prerequisite)  | Caron (e.g. pre-existing<br>trust led to lower<br>participation)          | Legault, Lethin,<br>Helgesen (e.g. low<br>trust led to heightened<br>supervision)<br>Boogaard (greater<br>trust linked to greater<br>FI) |
| Beliefs about dementia care  | Lau (e.g. realistic<br>expectations)   | Majerovitz (e.g. perceive<br>staff not doing best)                        |  |
| Beliefs and values/sense of<br>purpose   | Caron, Gladstone, Strang<br>(e.g. keep continuity)   |   |  |
| Emotional closeness to<br>resident   | Johansson, Helgesen,<br>Helgesen <sup>2</sup> , Strang   |   | Strang   |

(Continued)

**Table 7.** (Continued.)

| Agent (care home/staff or resident or family) and influential factor | How factor influences family involvement and paper references  |  |                                   |  |              |
|--|--|--|-----------------------------------|--|--------------|
|  | Overall  |  | On visits and contact             |  |              |
|  | Assists or stimulates  | Prevents or discourages  | Increases                         | Decreases  | No influence |
| Relationship (spouse)  | Helgesen <sup>2</sup> (when spouse vulnerability supported)  |  |                                   |  |              |
| Higher education level <sup>1</sup>                                  | Bramble <sup>3</sup> (e.g. engage with FI research)  | Helgesen <sup>2</sup> (e.g. more FI from people with non-tertiary) |                                   | Boogaard (no link between trust in staff and FI)       |              |
| Age and gender   | Helgesen <sup>2</sup> (e.g. eldest relatives supported more by staff, males' knowledge about resident lower) |  |                                   |  |              |
| Ethnicity  |  |  |                                   | Boogaard (linked to trust, overall trust linked to FI) |              |
| Additional intra-family involvement                                  |  |  |                                   | Gladstone  |              |
| Perceived own incompetence   |  |  | Caron (e.g. blind trust in staff) |  |              |
| Social network   | Bramble, Johansson   | Carter (if inadequate)   |                                   |  |              |
| Communication style  | Lau, Legault   |  |                                   |  |              |
| Emotional difficulty (control, sadness)                              | Majerovitz, Strang   |  | Gladstone, Bramble                |  |              |
| Guilt <sup>1</sup>   | Johansson, Strang, Majerovitz  |  | Gladstone                         |  |              |
| Competing demands (including own family, health)                     | Seiger Cronfalk  |  | Gladstone                         |  |              |

Notes: 1. Contradictory or competing findings. 2. Helgesen *et al.* (2015). 3. Bramble *et al.* (2011).

difference was indicated regarding the type of FI involving *Supervising, influencing and directing care*; studies from the USA, UK and Australia highlighted this theme more than studies from Canada, Asia, Europe and Scandinavia.

FI studies in underrepresented locations featuring a wide range of cultures will address the evidence imbalance, uncover differences in country and regional FI preferences (that support culturally sensitive, person- and family-centred care), and promote deeper understanding of inter-country and inter-culture barriers and facilitators of FI.

It is possible that underrepresentation of many locations is not purely due to a difference in religious, cultural social norms or availability of care homes. Life expectancy in Africa, Asia and South America is lower than Europe, Oceania and the USA (United Nations, 2017). Consequently, with fewer people living to an age when dementia is most likely to be diagnosed (Rizzi *et al.*, 2014), dementia research may be of lower priority in some regions.

Intergenerational factors specifically influencing FI with care homes, relating to residents living with dementia, do not appear to have been studied. Four papers briefly mentioned grandchildren, exclusively when describing participant characteristics (Gladstone *et al.*, 2006; Reinhardt *et al.*, 2015; Livingston *et al.*, 2017; Walmsley and McCormack, 2017). Only one paper compared different generations (spouse to adult child) involvement across multiple domains (Helgesen *et al.*, 2015), however, the youngest participant was 34 years of age. Another paper mentioned the need to clarify how differing relationship ties explain differences in decision making (Caron *et al.*, 2005). Future FI research needs to include care home settings, residents living with dementia and family participants under the age of 18.

Uninvolved and scarcely involved families rarely featured in the study samples. They may account for as many as 15 per cent of families (missing data cases reported by Livingston *et al.*, 2017). Research with families who have no or minimal involvement after placement of a relative living with dementia would ensure we understand if families have been discouraged from participation, have mismatched expectations about how they might participate, and whether opportunities for involvement exist or if there are other unknown influences preventing involvement. Studies with this sample group are likely to be challenging (Helgesen *et al.*, 2015), however, ignoring this sample can lead to bias and hinder a complete understanding (Craig *et al.*, 2013).

The literature would be enhanced by dementia-specific research exploring optimal levels of FI and conditions in which high levels of FI result in negative psychosocial, quality-of-life and care outcomes for residents. Development and evaluation of effective methods of communicating this evidence to families and negotiating a new involvement profile while maintaining a positive, collaborative, partnership approach would also be necessary.

To understand better the associations and interactions between specific factors that influence FI, further studies with consistent, robust multi-source measures of FI, large sample sizes and mixed-method designs would be appropriate. Drawing credible conclusions would then be feasible.

Finally, in the Introduction, the point was made that FI was key to transparency between patient, families and care home staff. It was interesting to discover that transparency as a distinct construct was not specifically examined in any of the



included studies. One study investigating advocacy found that staff transparency about incidents was critical in the development of trust in family–staff relationships (Legault and Ducharme, 2009). This finding is harmonious with the UK’s duty of candour regulation which aims to ensure an open, honest and transparent culture in care provision settings (CQC, 2015). Cohen *et al.* (2014) suggested increased transparency in roles and involvement would promote family–staff partnership.

Factors that negatively influence FI included inadequate information provision and staff communication, involvement not always being encouraged, family perceptions that staff are not doing their best, and lack of respect for or blind trust in staff. All of these are likely to hinder transparency, advocacy and relationships. Trust, openness and an inclusive environment are important factors in involvement (Petriwskyj *et al.*, 2014; Jakobsen *et al.*, 2019) and our review indicates there is a growing emphasis on open family–staff relationships and care home encouragement of involvement through policies and practice. The literature base may benefit from studies that go beyond investigating trust and openness. Instead, specific exploration of transparency in care homes, relating to families and residents living with dementia, may ensure further enhancement of FCC framework and related interventions.

## Conclusions

This dementia and care home-specific review explored types of FI and factors influencing FI. It also compared PCC and FCC principles to how families are (or wish to be) involved with residential care providers. Sound progress in our understanding has been made over the last 14 years and since publication of Gaugler’s (2005) seminal paper. However, many findings remain under-corroborated and gaps in the evidence exist.

Key messages include (not exclusively):

- (1) An invitation to participate is not enough; opportunities to undertake activities families expect to be involved in is likely to influence their level of engagement and their successful integration as a care partner.
- (2) There are seven themes of FI activities and individual types of FI that appear to fit well with current PCC and FCC principles. Despite this, more and specific clinical application and family-centred research is required. Exploration of inter-family variation, how and why the same influencing factor can impact FI both negatively and positively across and within families would be helpful.
- (3) There is a large, diverse range and complexity of factors influencing participation, including families’ varied perception of the importance of their involvement for resident wellbeing.
- (4) Intergenerational factors have yet to be studied.
- (5) Many countries, regions and cultures are underrepresented in the literature base.
- (6) Improved definitions of FI and PCC are proposed.

A final thought, while the coronavirus pandemic continues to impact resident and family wellbeing negatively, it is not a time to step back from advancing FI

principles. There is a need to adapt and use creative methodologies, including technology, to progress FI at all levels of care. This systematic review and the second paper in this series (Interventions promoting family involvement with care homes following placement of a relative living with dementia: A systematic review. (Hayward *et al.*, 2021) provide a comprehensive view of FI, including a proposed new definition, the nature of FI and process involved, how FI relates to PCC and FCC principles, measures of FI, the impact of FI on residents' wellbeing and how FI is being promoted in care homes. Together, the papers support researchers and care home providers to make informed decisions in the dementia field.

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\* Indicates articles included in the review.

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