

# Staff Factors Contributing to Family Satisfaction with Long-Term Dementia Care: A Systematic Review of the Literature

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**Author post-print (accepted) deposited by Coventry University's Repository**

**Original citation & hyperlink:**

Law, K, Patterson, TG & Muers, J 2016, 'Staff Factors Contributing to Family Satisfaction with Long-Term Dementia Care: A Systematic Review of the Literature' *Clinical Gerontologist*, vol (in press), pp. (in press)

<http://dx.doi.org/10.1080/07317115.2016.1260082>

DOI 10.1080/07317115.2016.1260082

ISSN 0731-7115

ESSN 1545-2301

Publisher: Taylor and Francis

**This is an Accepted Manuscript of an article published by Taylor & Francis in *Clinical Gerontologist* on 29<sup>th</sup> November 2016, available online:**

<http://www.tandfonline.com/10.1080/07317115.2016.1260082>

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**Staff factors contributing to family satisfaction with long-term  
dementia care: A systematic review of the literature.**

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Overall word count (excluding tables, figures and references): 5999

## 1. Abstract

*Objective:* The aim of the present review was to critically evaluate empirical evidence regarding staff factors that contribute to families' satisfaction with ongoing care provision for their relatives with dementia in long-term care.

*Methods:* Four databases were systematically searched using search terms informed by the aim of the present systematic review. The resulting 14 relevant articles comprised both qualitative and quantitative studies.

*Results:* The findings highlighted three broad areas relating to staff factors which appeared to contribute to families' satisfaction with care provision: *family related factors*, relating to staff interaction with families; *staffing related factors*, focusing on staffing organisation and composition; and *client related factors*, focusing on staff interaction with clients and the quality of care provided.

*Clinical Implications:* Families want consistent, knowledgeable staff who interact well and respond appropriately to the needs of their relative as well as their needs as family members. Staff training in such settings should therefore focus not only on staff education but also on the importance of establishing effective relationships with both clients and families.

*Conclusions:* The findings have important implications for care staff and managers working in such settings regarding staffing organisation, staff training, recruitment and retention. Future research directions are discussed.

**Key words:** Dementia, families, long-term care, satisfaction, staff factors

## **2. Introduction**

### **2.1 Person-Centred Dementia Care**

In the United Kingdom (UK) several high profile reports have emphasised the importance of high quality care provision within long-term care settings (e.g. Department of Health (DOH), 2012); including in facilities for people with dementia (PwD) (e.g. Care Quality Commission (CQC), 2013). Indeed, the CQC have outlined their determination to help ensure that PwD receive high-quality care, arguing that a personalised approach is key (CQC, 2014).

Person-centred dementia care has been said to include four major elements: valuing PwD, treating them as individuals, viewing the world from their perspective and creating a social environment which promotes their wellbeing (Brooker, 2004). A person-centred approach also emphasises the importance of considering family members and in particular, how to support and enhance their input to their relative (National Institute for Health and Care Excellence, 2006).

Families are recognised as playing an integral role in educating staff and in maintaining normality and continuity for PwD residing in long-term care (Alzheimer's Society of Canada (ASC), 2011). Indeed, guidelines for person-centred care in such settings state that staff should encourage and support family involvement and treat families as valued members of the care team (ASC, 2011). However, recent guidance acknowledges that there is only limited evidence regarding how best to support families and recommends further research to better understand their needs (DOH, 2015). Arguably in order to provide person-centred dementia care which recognises

and supports families, it is essential to understand their perspective and what contributes to their satisfaction with care provision.

## **2.2. Family Satisfaction with Long-Term Dementia Care**

Previous research has explored families' satisfaction with care provision for PwD in long-term care. For example, research examining family satisfaction with different aspects of care found that, overall, families reported high satisfaction initially which remained high over time (Janzen & Warren, 2005). Furthermore, another study concluded that families were highly satisfied with all aspects of care provision (Lubart et al., 2004). Nevertheless, other studies have reported less favourable satisfaction. For example, researchers evaluating family perceptions of an Alzheimer's unit found that families were most dissatisfied with not being asked to participate in their relative's care, staff availability and the variety and number of activities available (Maas, Buckwalter & Kelley, 1991). In a more recent study family members of PwD in nursing homes expressed concerns about the quality of personal care and dissatisfaction regarding communication from professionals (Givens et al., 2012).

Quantitative studies have attempted to ascertain which factors in particular appear to contribute to families' overall satisfaction. For example, Levy-Storms and Miller-Martinez (2005) examined the relationship between family involvement and satisfaction with care. At admission, more depressed family caregivers and those assisting their relative with activities of daily living (ADLs) reported lower satisfaction; and one year later those providing assistance with ADLs and those whose relatives had behavioural problems were less satisfied with care (Levy-Storms & Miller-Martinez, 2005). Additionally, in another study examining family satisfaction with

nursing home care for PwD, seven variables were found to be associated with higher family satisfaction, including having less involvement with direct hands-on care and having higher expectations of care provision (Tornatore & Grant, 2004).

### **2.3. Family Perceptions of Long-Term Dementia Care**

Whilst literature using a quantitative methodology has allowed researchers to identify factors which contribute to families' satisfaction, such methodology does not enable the exploration of why these factors are important. Studies utilising qualitative methodology have attempted to fill this gap by exploring families' perceptions of long-term care for PwD. Two systematic reviews of qualitative literature in this area have focused on families' experiences of transition into long-term care and end of life care (Hennings, Froggatt & Keady, 2010; Graneheim, Johansson & Lindgren, 2014).

Firstly, Hennings et al. (2010) conducted a systematic literature review of family experiences of end of life care for PwD in care homes. They found that families felt unknowledgeable about the process of dying with dementia and wanted staff to explain and discuss treatment options. However, families described communication as poor or non-existent at a time when they wanted frequent contact, for staff to demonstrate understanding and empathy and to provide reassurance, guidance and support with decision making (Hennings et al., 2010). The authors concluded that families seek communication, guidance and companionship from staff; but argued for further research to better understand families' needs (Hennings et al., 2010).

Secondly, Graneheim et al. (2014) conducted a meta-ethnographic study incorporating a systematic literature search relating to families' experiences of

transition into long-term care. They found this was a unique experience for families; involving monitoring care and becoming a spokesperson for their relative. Families wanted to influence care and for staff to show a genuine interest and to take their opinions into account. However, some highlighted difficulties in communication and commented negatively about lack of activities available. The authors concluded that the process of PwD and their families adapting to long-term care could be facilitated by staff recognising families as partners in care (Graneheim et al., 2014).

#### **2.4. Staff Factors and Family Satisfaction with Care Provision**

The aforementioned literature reviews (Hennings et al., 2010; Graneheim et al., 2014) indicated that several staff factors seemed to contribute to families' satisfaction with care provision. For example, staff providing good communication, support and guidance to families as well as providing adequate activities for PwD **were contributing factors** (Hennings et al., 2010; Graneheim et al., 2014). Such factors are important considerations because it is these factors over which care home managers and dementia policy advisors have some control. Given that considering how to enhance and support family input to PwD is recognised as important for person-centred care (NICE, 2006), it seems pertinent that staff factors contributing to families' satisfaction with care are further explored.

#### **2.5. Rationale for Present Review**

Two previous literature reviews focusing on the experiences of family members of PwD in long-term care have been conducted (Hennings et al., 2010; Graneheim et al., 2014). These focused on specific periods of transition: moving to a care home and the

end of life. Although both considered staff factors that may contribute to family satisfaction with care, families may have unique needs and expectations of staff at these particular points of transition; and different staff factors may be relevant outside these two specific periods. Therefore, a review of the empirical literature focussing more broadly on staff factors contributing to families' satisfaction with ongoing care provision appears to be warranted.

## **2.6. Aim**

The aim of the present systematic review was to critically evaluate the existing empirical evidence regarding staff factors that contribute to families' satisfaction with ongoing care provision for PwD in long-term care. Both qualitative and quantitative literature were considered, providing that findings were reported on staff factors that may potentially contribute towards families' satisfaction with care provision.

## **3. Method**

### **3.1. Search Strategy**

#### **3.1.1. Database Search**

A systematic literature search was conducted to identify relevant articles from the following bibliographic databases: PubMed, Cumulative Index of Nursing and Allied Health Literature (CINAHL), Scopus and MEDLINE. Searches were performed using the terms outlined in Table 1.1. The search was not confined to a specific time period; although articles published after January 2015 were not considered.



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<p>dementia <b>OR</b> Alzheimer*</p> <p><b>AND</b></p> <p>spouse <b>OR</b> famil* <b>OR</b> caregiver* <b>OR</b> carer* <b>OR</b> relative*</p> <p><b>AND</b></p> <p>experience* <b>OR</b> view* <b>OR</b> opinion* <b>OR</b> perception* <b>OR</b> perspective* <b>OR</b> attitude*</p> <p><b>OR</b> outlook <b>OR</b> stance <b>OR</b> account* <b>OR</b> satisfaction <b>OR</b> dissatisfaction</p> <p><b>AND</b></p> <p>“care home*” <b>OR</b> “care facility*” <b>OR</b> “residential home*” <b>OR</b> “residential care” <b>OR</b></p> <p>“nursing home*” <b>OR</b> “nursing care” <b>OR</b> “long term care” <b>OR</b> “long-term care” <b>OR</b></p> <p>“group living” <b>OR</b> “group home*” <b>OR</b> “homelike facilit*” <b>OR</b> “specialised care” <b>OR</b></p> <p>“specialized care” <b>OR</b> “group home living”</p>
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**Table 1.1: Database Search Terms**

Each reference generated was screened and those obviously unrelated to the review aim were discarded. The abstracts of potentially relevant articles were read and if relevant the full article was located and screened against the inclusion and exclusion criteria outlined in Table 1.2. The reference list of all relevant articles was manually searched to identify additional articles which were screened in accordance with the search strategy above. Although several full articles were considered, no further relevant articles were obtained via the manual search.

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Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>• Studies which report on the perceptions of family members whose relatives have dementia</li> </ul>	<ul style="list-style-type: none"> <li>• Studies which report on the perceptions of family members whose relatives attend day care or respite care rather than residing in long-term care</li> </ul>
<ul style="list-style-type: none"> <li>• Studies which report on the perceptions of family members whose relatives reside in long-term care (e.g. nursing homes, residential homes)</li> </ul>	<ul style="list-style-type: none"> <li>• Studies in which staff factors are only a peripheral focus of the article</li> </ul>
<ul style="list-style-type: none"> <li>• Studies in which staff factors feature centrally in the results section of the article</li> </ul>	<ul style="list-style-type: none"> <li>• Studies in which it was not possible to separate data from family members of people with dementia from data gathered from staff members working with people with dementia or from people with dementia themselves</li> </ul>
<ul style="list-style-type: none"> <li>• Studies in which relevant staff factors as perceived by family members of people with dementia are clearly identifiable in the results section</li> </ul>	<ul style="list-style-type: none"> <li>• Studies in which the transition from living in the community to long-term care was the central focus of the research</li> </ul>
<ul style="list-style-type: none"> <li>• Studies which have been published in peer-reviewed academic journals</li> </ul>	
<ul style="list-style-type: none"> <li>• Studies published in English</li> </ul>	<ul style="list-style-type: none"> <li>• Studies in which end of life care was the central focus of the research</li> </ul>

**Table 1.2: Article Inclusion and Exclusion Criteria**

### 3.3. Search Results

Following the systematic search 14 articles met the inclusion criteria. Figure 1.1 outlines the study selection process in line with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, Altman & The PRISMA Group, 2009).

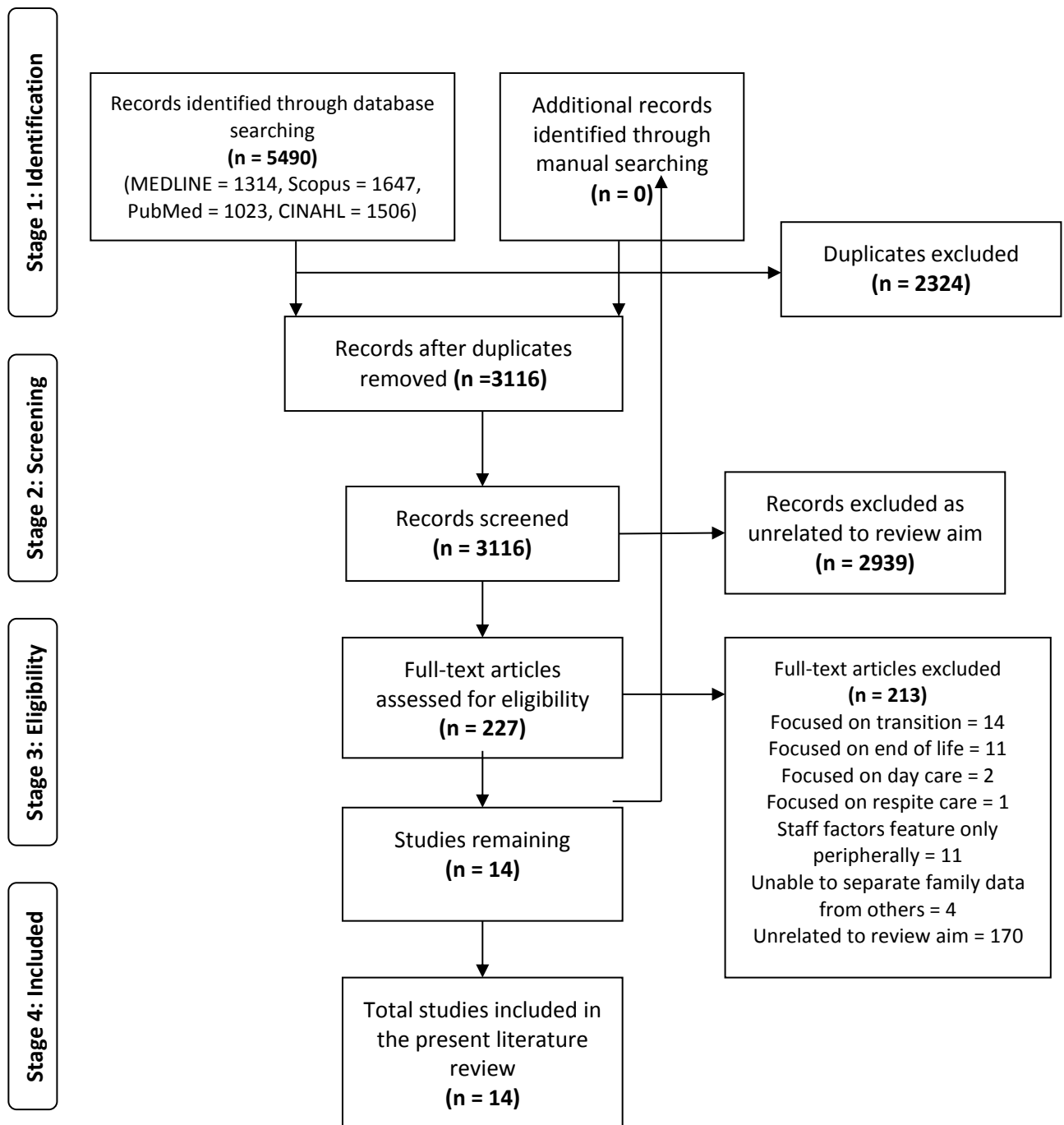


Figure 1.1: An adapted PRISMA flow diagram of the study selection procedure (Moher et al., 2009)

### **3.4. Assessment of Quality**

The final 14 articles were appraised using a quality checklist developed by Caldwell, Henshaw and Taylor (2005); specifically designed to provide a framework for critiquing health-related research incorporating both quantitative and qualitative methodology. This checklist was chosen due to the review topic and the inclusion of both qualitative and quantitative research. The quality scores obtained were considered tentatively and were used to critically evaluate each study's strengths and limitations rather than as a basis for inclusion or exclusion into the review. Table 1.3 outlines the quality scores for each article.

To enhance reliability two studies were independently rated by another researcher and the scores were compared and discussed. Statistical analysis to determine inter-rater reliability using a Kappa coefficient revealed a perfect agreement in the ratings for one study (i.e. a Kappa coefficient could not be generated); and a two-point difference for the other, yielding a Kappa coefficient of  $k = .550$ ,  $p = .005$  (95% CI: .121 - .979); indicating a moderate level of agreement (Landis & Koch, 1977).

### **3.5. Critical Analysis of Studies**

#### **3.5.1 Overview**

Thirteen studies scored between 26 and 36 out of a maximum 36 points, demonstrating reasonably consistent high ratings on the quality indicators. One study scored 7 (Shields Scott, 1991) indicating substantial weaknesses. The paper was relatively brief, which may account for the absence of information relevant to the quality checklist criteria. Nonetheless it was retained due to its relevance to the

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review; though its findings should be interpreted cautiously in the absence of a more robustly designed replication study. Table 1.3 presents the general characteristics of each study (incorporating only details relevant to the present review).

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**Table 1.3: Characteristics of the studies reviewed**

Author, year of publication, country of origin and quality checklist score	Aims, research questions and topics covered or dependent and independent variables	Sample size, participant details: gender, age, ethnicity and relationship to person with dementia	Recruitment strategy and location	Data collection and data analysis	Key findings
<p><u>Author:</u> Bramble, Moyle &amp; McAllister</p> <p><u>Year of publication:</u> 2009</p> <p><u>Country of origin:</u> Australia</p> <p><u>Quality checklist score:</u> 32/36</p>	<p><u>Aim:</u> To provide in-depth descriptions of the experiences of family caregivers when placing their relative with dementia in long-term care</p> <p><u>Research question:</u> What does it mean to be a family caregiver of a relative with dementia who is placed in Long Term Care?</p> <p><u>Topics covered:</u> -Caregiving prior to placement -The process and feelings associated with placement -Perceptions of the care relationships with staff -Evaluation of the care facility</p>	<p><u>Sample size:</u> N = 10</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Not specified</p> <p><u>Gender:</u> Male = 3, Female = 7</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Spouse = 3, Child = 7</p>	<p><u>Recruitment strategy:</u> Purposive sampling</p> <p>Managers at two long-term care study sites assisted in identifying family caregivers who were invited by postal invitations, on-site information sessions and via telephone</p> <p><u>Location:</u> Brisbane, Australia</p> <p>Participants' relatives with dementia lived in a range of long-term care settings: hostel (low care), nursing home (high care) or dementia special care unit</p>	<p><u>Data collection:</u> Descriptive qualitative approach with semi-structured interviews</p> <p>Questions designed so participants could tell their story and voice their views. Questions were worded to elicit knowledge based on experience and feelings</p> <p>Interviews lasted 1 hour on average and were conducted at the long-term care setting or the participant's home</p> <p><u>Data analysis:</u> Not explicitly specified. Major topics were summarised and coded for comparison across participants and the identification of themes</p>	<p>Four themes emerged:</p> <p><i>-Increasing burden and isolation:</i> related to families' experiences of increasing burden of care and a sense of isolation as they lost social contact prior to their relative's admission</p> <p><i>-Relentless grief:</i> related to the loss, sadness and guilt families experienced after their relative's admission</p> <p><i>-Seeking connection and meaning with staff:</i> related to how families experienced their relationships with staff</p> <p><i>-Looking after the person:</i> related to families' perceptions regarding the care provided to their relative</p>
<p><u>Author:</u> Duncan &amp; Morgan</p> <p><u>Year of publication:</u> 1994</p>	<p><u>Aim:</u> To understand family caregivers' perspectives on the nature of family-staff relationships in formal care</p> <p><u>Research questions:</u> -What staff did family</p>	<p><u>Sample size:</u> N = 179</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Average age 62 (range 33-87)</p>	<p><u>Recruitment strategy:</u> Method not specified</p> <p>Participants were recruited via post to the Alzheimer's Disease Association contact list, visits to local support</p>	<p><u>Data collection:</u> 30 focus groups each comprising of four to nine participants and lasting approximately 45 minutes</p> <p>10 individual interviews with 4 adult children and 6</p>	<p>Results were presented in terms of three main areas:</p> <p><i>-Categories of staff mentioned:</i> Participants made both positive and negative statements about nursing staff, administrative staff, aides and the facility staff in general</p>

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Author, year of publication, country of origin and quality checklist score	Aims, research questions and topics covered or dependent and independent variables	Sample size, participant details: gender, age, ethnicity and relationship to person with dementia	Recruitment strategy and location	Data collection and data analysis	Key findings
<p><u>Country of origin:</u> United States of America (USA)</p> <p><u>Quality checklist score:</u> 29/36</p>	<p>caregivers mention most often? -Which staff behaviours were most important to them? -How did family caregivers interpret and evaluate staff behaviours?</p> <p><u>Topics covered:</u> -What makes caregiving easier or harder for family caregivers -How the kind of caregiving family caregivers provide at home differs from the kind of caregiving they provide when their relative is in a formal care setting -Experiences of contact with staff including the staff behaviours most important to them and how they evaluated staff behaviours</p>	<p><u>Gender:</u> Male = 25%, Female = 75%</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Spouse = 76, Child = 103</p>	<p>groups and contacts with formal care settings</p> <p><u>Location:</u> Greater Portland, Oregon</p> <p>Participants' relatives resided in either foster care or nursing homes</p>	<p>spouses from the original study</p> <p>A non-directive approach to interviewing was used to allow participants to pursue topics of most importance to them</p> <p><u>Data analysis:</u> Qualitative version of content analysis. Transcripts were coded based on positive or negative references to staff and then summarised to obtain themes related to the staff behaviours most likely to generate positive and negative comments. Use of an Ethnograph software package</p>	<p><i>-Most important staff behaviours:</i> Participants mentioned staff behaviours such as their relationship with client, their relationship with families and their approach to technical tasks</p> <p><i>-How staff behaviours were interpreted and evaluated:</i> The quality of care staff delivered to their relative mattered most in terms of their interpretations and evaluations of staff behaviour</p>
<p><u>Author:</u> Edvardsson, Fetherstonhaugh &amp; Nay</p> <p><u>Year of publication:</u> 2010</p> <p><u>Country of origin:</u></p>	<p><u>Aim:</u> To describe the content of person-centred care as described by people with dementia, their family members and staff in residential aged care</p> <p><u>Research question:</u> Not explicitly specified</p>	<p><u>Sample size:</u> N = 12</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Not specified</p> <p><u>Gender:</u> Not specified</p> <p><u>Ethnicity:</u> Not specified</p>	<p><u>Recruitment strategy:</u> Convenience sampling</p> <p>A flyer was placed in the Alzheimer's Australia newsletter and those interested who had experience of public or private residential aged care</p>	<p><u>Data collection:</u> Face-to-face interviews with those living in metropolitan areas in their own homes</p> <p>Phone interviews with those living in rural areas</p> <p>Interviews lasted between</p>	<p>The core of person-centred care was experienced as promoting a continuation of self and normality. Five categories were identified as contributing to this:</p> <p>-Knowing the history, preferences, interests and particularities of the person</p>

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<p>Australia</p> <p><u>Quality checklist score:</u> 33/36</p>	<p><u>Topics covered:</u></p> <ul style="list-style-type: none"> <li>-What person-centred care was perceived to be</li> <li>-The meaning of high-quality or low-quality care in residential facilities</li> <li>-Experiences of residential care</li> <li>-On what grounds a decision was made about which aged care facility the person with dementia would live in</li> </ul>	<p><u>Relationship to person with dementia:</u> Not specified</p>	<p>responded by telephoning the researcher</p> <p><u>Location:</u> Victoria, Australia</p> <p>No details were specified about the residential aged care facilities</p>	<p>45 minutes to 2 hours. No details about the interview approach were specified except that the qualitative approach was used to obtain rich descriptions of person-centred care</p> <p><u>Data analysis:</u> Qualitative content analysis</p>	<ul style="list-style-type: none"> <li>-Family members being welcomed into the life and care of the person</li> <li>-Meaningful activities that were adapted to the person’s ability level</li> <li>-Being in a personalised environment (e.g. personal things, pleasant environment)</li> <li>-Flexibility and continuity (e.g. flexible routines, available and present staff, staff consistency)</li> </ul>
<p><u>Author:</u> Ejaz, Noelker, Schur, Whitlatch &amp; Looman</p> <p><u>Year of publication:</u> 2002</p> <p><u>Country of origin:</u> United States of America (USA)</p> <p><u>Quality checklist score:</u> 29/36</p>	<p><u>Aim:</u> To test a preliminary model to explain family satisfaction with nursing home care</p> <p><u>Research question:</u> How are family members’ perceptions of the quality of care provided to their institutionalised relatives affected by:</p> <ul style="list-style-type: none"> <li>-placement-related stress</li> <li>-their involvement in resident care and nursing home services</li> <li>- the type of care they think nursing assistants provide</li> <li>- family –staff interactions?</li> </ul>	<p><u>Sample size:</u> N = 133</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Mean age = 61 (range 34-90)</p> <p><u>Gender:</u> Male = 30%, Female = 70%</p> <p><u>Ethnicity:</u> 84% Caucasian (other ethnicities not specified)</p> <p><u>Relationship to person with dementia:</u> 67% adult children (other relationships not specified)</p>	<p><u>Recruitment strategy:</u> Convenience sampling</p> <p>Each nursing home provided contact information for the primary family caregivers of residents with dementia. Families were sent a letter outlining the study and were then telephoned by the researchers to screen them using the eligibility criteria</p> <p><u>Location:</u> Five suburban nursing facilities in the greater Cleveland area</p>	<p><u>Data collection:</u> Cross-sectional survey design to conduct in-person structured interviews with family members</p> <p>The interview location was not specified</p> <p><u>Data analysis:</u> Two separate ordinary least squares multiple regression analyses were used to examine improvements needed in environment and</p>	<p>More than 40% of relatives believed improvement was needed in:</p> <ul style="list-style-type: none"> <li>-Manner in which complaints and concerns are handled</li> <li>-Amount of care received</li> <li>-Personalised attention</li> <li>-Care given by nursing assistants</li> </ul> <p>Families perceived significant improvements were needed:</p> <p>1)in environment/admin when:</p> <ul style="list-style-type: none"> <li>-They had negative interactions with other staff</li> <li>- The care by nursing assistants was not perceived to be sensitive</li> <li>- Family members gave more activities of daily living (ADL) help to their relative</li> </ul>



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	<p><u>-Dependent variable:</u> -Family member’s perceptions of quality of care assessed as a multidimensional construct comprising of 13 service/care areas and 2 staff areas using a Likert-scale assessing whether improvement was needed in each area</p> <p><u>-Independent variables:</u> -Family adjustment to nursing home placement -Family involvement with resident care -Type of care provided by nursing assistants -Family-staff interactions</p>		<p>Two facilities were proprietary and three were non-profit. Four had special care units and they ranged in size from 82 to 203 beds. The nursing homes offered a range of care levels; however these were not defined</p>	<p>administration, and direct care</p>	<p><u>2) in direct care when:</u> -They had negative interactions with other staff -Family members gave more ADL help to their relative</p>
<p><u>Author:</u> Hertzberg &amp; Ekman</p> <p><u>Year of publication:</u> 2000</p> <p><u>Country of origin:</u> Sweden</p> <p><u>Quality checklist score:</u> 33/36</p>	<p><u>Aim:</u> To identify and describe obstacles to a well-functioning relationship between relatives and staff in order to suggest promoters of a well-functioning relationship</p> <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u> Topics for discussion were not chosen by the researcher and the researcher did not act as a</p>	<p><u>Sample size:</u> N = 10</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Average age = 64 (range 40-80)</p> <p><u>Gender:</u> Male = 2, Female = 8</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Spouse =</p>	<p><u>Recruitment strategy:</u> Participants applied for participation following an advertisement in the Dementia Association’s local journal. Representatives of the Dementia Association (not the researcher) made the selection of participants</p> <p><u>Location:</u> Not explicitly stated</p>	<p><u>Data collection:</u> Non-participant observation of focus groups</p> <p>Three different groups (A, B and C) met six times, once every six weeks. Focus groups lasted 90 minutes</p> <p>Each group had a professional group leader and a representative of the Dementia Association who</p>	<p>Three main categories emerged:</p> <p><i>-Influence and participation:</i> related to families’ experiences of being asked questions and encouraged to participate by staff in the care of their relative. It also covered their experiences of activities for their relative with dementia.</p> <p><i>-Uncertainty and distrust:</i> related to examples of families experiencing uncertainty and distrust in their relationships with staff</p>

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	<p>moderator during the discussions</p> <p>Participants were encouraged to pursue topics which were of most concern to them. However, the group leaders occasionally directed them towards the task of the group: to discuss factors that could enhance understanding and relationships between staff and relatives.</p>	<p>5, Child = 3, Sibling = 1, Niece = 1,</p>	<p>No details were provided about the long-term care setting in which participants' relatives resided</p>	<p>acted as a participant and as an assistant to the leader. Each group had three relatives and three staff members. The researcher acted as a silent non-participant in the discussions</p> <p><u>Data analysis:</u> Sentence by sentence analysis inspired by the constant comparative method. Codes were generated based on the text and through constant comparison of these codes three categories emerged</p>	<p><i>-Communication difficulties:</i> related to different aspects of communication between families and staff including information, conversations, opinions and questions. It also concerned the difficulties experienced by families in their interactions with staff members</p>
<p><u>Author:</u> Legault &amp; Ducharme</p> <p><u>Year of publication:</u> 2009</p> <p><u>Country of origin:</u> Canada</p> <p><u>Quality checklist score:</u> 33/36</p>	<p><u>Aim:</u> To explain the transformation of the advocacy role of daughter carers following the admission of an elderly parent with dementia to a long-term care facility</p> <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u> -Personal, relational and contextual conditions that</p>	<p><u>Sample size:</u> N = 14</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Average age = 55 (range = 44-65)</p> <p><u>Gender:</u> Male = 0, Female = 14</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Child = 14</p>	<p><u>Recruitment strategy:</u> Theoretical sampling (participants chosen based on their theoretical relevance to the study rather than how representative they are of the population)</p> <p>A nurse contacted the possible participants and requested permission to forward their names to the researchers. The researcher then contacted them by</p>	<p><u>Data collection:</u> Interviews lasting approximately 90 minutes were conducted at the participant's home, the nursing home or the research centre</p> <p>An interview guide was developed but this evolved as a function of the results of the analysis, in line with a grounded theory approach. The initial interview guide contained</p>	<p>Transformation of the advocacy role implicated three tightly interrelated intermediary processes:</p> <ul style="list-style-type: none"> <li>-Development of trust in the care setting</li> <li>-Integration of the setting</li> <li>-Evaluation of quality of care</li> </ul> <p><i>Developing trust in the facility and its staff</i> appeared to be at the core of the transformation of the advocacy role. Five factors were found to be associated with the establishment of trust:</p>

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	<p>influence transformation of the advocacy role</p> <ul style="list-style-type: none"> <li>-The actions and interactions that the advocacy role entails</li> <li>-The consequences of the advocacy role for participants and their institutionalised parents</li> </ul>	<p>Participants' relatives with dementia had been institutionalised for at least six months</p>	<p>telephone to explain the research and obtain consent</p> <p><u>Location:</u> Quebec, Canada</p> <p>Participants were recruited from three long-term care facilities (one specialised university geriatrics institute, two nursing homes). One nursing home was located in a middle-class residential area and the other in a less privileged neighbourhood. No further details about the care settings were provided</p>	<p>five open-ended questions covering the general topics related to the phenomenon under study</p> <p><u>Data analysis:</u> Grounded theory</p> <p>Simultaneous data collection and analysis with the first interview immediately analysed and the results obtained used to determine the theoretical sampling and questions for further participants</p>	<ol style="list-style-type: none"> <li>1)Quality of contact with staff on admission and information provided</li> <li>2)Comparisons with other nursing homes</li> <li>3)Staff demonstrating interest in clients</li> <li>4)Staff responsiveness to family concerns</li> <li>5)Transparency in the event of accidents or incidents</li> </ol> <p><i>Integration of the setting:</i></p> <ul style="list-style-type: none"> <li>-Establishing a relationship of reciprocity with staff</li> <li>-Collaborating with staff</li> <li>-Diplomatic communication style</li> </ul> <p><i>Evaluation of quality of care:</i></p> <ul style="list-style-type: none"> <li>-Exercising judgment on quality of care</li> <li>-Weighting that judgment</li> <li>-Acting to change the situation</li> </ul>
<p><u>Author:</u> Looman, Noelker, Schur, Whitlatch &amp; Ejaz</p> <p><u>Year of publication:</u> 1997</p> <p><u>Country of origin:</u> United States of America (USA)</p>	<p><u>Aim:</u> Not explicitly specified. The study focuses on family members' positive perceptions of the care provided by nursing assistants</p> <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u> -Family members' positive</p>	<p><u>Sample size:</u> N = 113</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Average age = 60 (range = 34-90)</p> <p><u>Gender:</u> Male = 40, Female = 93</p>	<p><u>Recruitment strategy:</u> Not explicitly specified</p> <p><u>Location:</u> Cleveland, Ohio</p> <p>Participants were recruited from five skilled nursing facilities (four of which had special care units for memory impaired residents). The sites ranged in size from</p>	<p><u>Data collection:</u> Structured in-person interviews</p> <p>The interview schedule was comprised of close-ended and open-ended questions</p> <p><u>Data analysis:</u> Content analysis</p> <p>All comments were reviewed to determine</p>	<p>Four themes emerged:</p> <ul style="list-style-type: none"> <li>-<i>Constraints on nursing assistants:</i> related to families' appreciation of the difficult role that nursing assistants have working with clients with dementia</li> <li>-<i>Care exceeding expectations:</i> related to family members' reports of care provided by nursing assistants that had exceeded their expectations</li> </ul>

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Author, year of publication, country of origin and quality checklist score	Aims, research questions and topics covered or dependent and independent variables	Sample size, participant details: gender, age, ethnicity and relationship to person with dementia	Recruitment strategy and location	Data collection and data analysis	Key findings
<p><u>Quality checklist score:</u> 26/36</p>	<p>perceptions of the care provided by nursing assistants -What had happened in the facility with regard to nursing assistants that had pleased or bothered family members the most -Areas of satisfaction or dissatisfaction with the nursing home</p>	<p><u>Ethnicity:</u> 83.5% Caucasian (other ethnicities not specified)  <u>Relationship to person with dementia:</u> Spouse = 24, Child = 89 (other relationships not specified)</p>	<p>82 to 203 beds. Three of the facilities were philanthropic and two were proprietary. One was a Catholic home; although all accepted residents regardless of their religious orientation</p>	<p>their basic substance and then four conceptual categories were identified and refined through systematic review of the interview schedules. Responses were content analysed and independently coded using the categories</p>	<p><i>-Nursing assistant expressiveness:</i> related to families' experiences of the positive physical and verbal expressions from nursing assistants towards their relatives  <i>-Family-like relationships:</i> related to families' perceptions of the kin-like relationship that developed between nursing assistants and their relatives</p>
<p><u>Author:</u> MacDonald  <u>Year of publication:</u> 2006  <u>Country of origin:</u> Canada  <u>Quality checklist score:</u> 28/36</p>	<p><u>Aim:</u> To investigate which aspects of the institutional environment impacts leisure opportunities and choices of individuals with Alzheimer's disease in a long-term care facility from the perspectives of professionals and family caregivers  <u>Research question:</u> Not explicitly specified  <u>Topics covered:</u> -How the environment impacts on leisure -Fun and enjoyable activities and why residents with Alzheimer's disease could not participate in these activities</p>	<p><u>Sample size:</u> N = 5  <u>Participant details:</u>  <u>Age:</u> Not specified  <u>Gender:</u> Not specified  <u>Ethnicity:</u> Not specified  <u>Relationship to person with dementia:</u> Both spouses and adult children of people with Alzheimer's disease participated; however the exact composition was not explicitly specified</p>	<p><u>Recruitment strategy:</u> Not explicitly specified  Potential participants who met the eligibility criteria were contacted by the researcher  <u>Location:</u> Not explicitly specified  Participants were recruited from a 120-bed long-term care facility which did not have a specialised care unit for people with Alzheimer's disease</p>	<p><u>Data collection:</u> Self-contained focus groups  A semi-structured approach was used whereby interview guides contained broad questions that attempted to elicit relevant information from participants  <u>Data analysis:</u> Thematic analysis  The focus group data was analysed by identifying recurring themes. The data was also analysed by an external individual and the researcher met with this</p>	<p>The following themes emerged:  <i>-Lack of staff:</i> related to family members' concerns about the lack of staff and the consequences this had on their relatives  <i>-Family involvement:</i> related to family members' feelings of guilt because they could no longer provide care to their family member  <i>-Concerns for well-being of loved one:</i> related to family members' concerns about the day-to-day comfort of their relatives  <i>-Physical environment:</i> related to family members' concerns about the physical environment in the facility</p>

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Author, year of publication, country of origin and quality checklist score	Aims, research questions and topics covered or dependent and independent variables	Sample size, participant details: gender, age, ethnicity and relationship to person with dementia	Recruitment strategy and location	Data collection and data analysis	Key findings
	<p>-Ways to enhance the quality of life of individuals with Alzheimer’s disease</p> <p>-What causes residents to become unhappy or uncomfortable</p>			<p>person to compare the themes that had emerged</p>	<p><i>-Opportunity for leisure was limited:</i> related to family members’ concerns about their relatives no longer participating in leisure activities</p>
<p><u>Author:</u> Moyle et al</p> <p><u>Year of publication:</u> 2014</p> <p><u>Country of origin:</u> Australia</p> <p><u>Quality checklist score:</u> 30/36</p>	<p><u>Aim:</u> To explore family members’ perceptions of what it means to value a person with dementia and how this might influence the quality of life of people with dementia</p> <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u></p> <ul style="list-style-type: none"> <li>-How family members and others valued their relative and how this influenced the quality of life of the person</li> <li>-The type of care provided</li> <li>-Their view of the role of caring for people with dementia</li> <li>-How people with dementia are valued by society</li> <li>-The impact of care provided by staff on the quality of life of the person with dementia</li> </ul>	<p><u>Sample size:</u> N = 20</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Not specified</p> <p><u>Gender:</u> Male = 4 , Female = 15 (gender unclear for 1 participant)</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Spouse = 2, Child = 15, Grandchild = 1, Niece =1, Friend = 1</p>	<p><u>Recruitment strategy:</u> Convenience sampling</p> <p>No further recruitment details were explicitly specified</p> <p><u>Location:</u> New South Wales and Queensland, Australia</p> <p>Participants were recruited from four mixed-gender long term care facilities which were all owned by the industry aged care partner. All facilities provided low (assisted living), high (nursing home) and special (dementia-specific) care and they ranged in size from 50-125 beds</p>	<p><u>Data collection:</u> Interviews</p> <p>Pragmatic, exploratory qualitative approach using a semi-structured interview schedule to engage family members in a discussion</p> <p><u>Data analysis:</u> Assisted by a Leximancer computer-assisted concept-mapping programme to help identify key concepts or themes and their interrelationships. The concepts are rank-ordered in terms of their importance</p>	<p>Three main factors were found to be influencing the person with dementia being valued and their quality of life:</p> <p><i>-The resident’s room:</i> this related to the importance of the physical environment for the person with dementia</p> <p><i>-The resident’s day:</i> this related to family members’ views regarding the importance of care staff taking time in their relative’s day to spend time with them, provide activities and get to know them</p> <p><i>-The resident:</i> this related to how the family member perceived and valued the person with dementia</p>
<p><u>Author:</u></p>	<p><u>Aim:</u> To focus on the lived experience of spouses of those</p>	<p><u>Sample size:</u> N = 10</p>	<p><u>Recruitment strategy:</u> Opportunistic sampling</p>	<p><u>Data collection:</u> Semi-structured interviews</p>	<p>Four themes emerged:</p>

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Author, year of publication, country of origin and quality checklist score	Aims, research questions and topics covered or dependent and independent variables	Sample size, participant details: gender, age, ethnicity and relationship to person with dementia	Recruitment strategy and location	Data collection and data analysis	Key findings
<p>Mullin, Simpson &amp; Froggatt</p> <p><u>Year of publication:</u> 2011</p> <p><u>Country of origin:</u> United Kingdom (UK)</p> <p><u>Quality checklist score:</u> 36/36</p>	<p>with dementia in long-term care in order to aid understanding and help develop appropriate information and support for this group of people</p> <p><u>Research questions:</u>                      -What are the experiences of spouses/partners of individuals with dementia in care homes?                      -What meanings do the participants give to their experiences?</p> <p><u>Topics covered:</u>                      -Experiences following placement of their relative                      -Support                      -The spousal relationship                      -Aspects relating to the care home                      -Thoughts about the future</p>	<p><u>Participant details:</u></p> <p><u>Age:</u> Average Age = 73 (range = 54-89)</p> <p><u>Gender:</u> Male = 6, Female = 4</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Spouse = 9, Long-term partner = 1</p>	<p>Participants were identified through information packs distributed via care home managers. They were asked to return a consent form after which they were contacted by the researcher</p> <p><u>Location:</u> North-West England</p> <p>Care homes were identified through the Commission for Social Care Inspection</p> <p>Care homes recruited were within the private sector and had specific dementia care provision, a minimum quality rating of two stars and a minimum capacity of 20 beds</p>	<p>Interviews were conducted at the participant's home or the nursing home and lasted between 50 minutes and 1 hour. An interview schedule with prompts was used as a guide</p> <p><u>Data analysis:</u> Interpretative Phenomenological Analysis (IPA)</p> <p>Initial notes written on the transcripts were used to identify possible subthemes which were then analysed to identify relationships between them and rearranged or merged together. This was repeated for each participant and compared to produce overall themes</p>	<p><i>-Identity: 'till death us do part':</i> related to the identity of the participants in relation to the spousal relationship</p> <p><i>-Making sense of change:</i> related to the changes family members experienced as their relative with dementia deteriorated</p> <p><i>-Relationship with care provided: Visiting as surveillance:</i> related to family members' perceptions of care and the need for ongoing scrutiny with regards to the care provided</p> <p><i>-Relationship to the future: hope versus despair:</i> related to family members' feelings about the future</p>
<p><u>Author:</u> Palmer</p> <p><u>Year of publication:</u> 2012</p>	<p><u>Aim:</u> Not explicitly specified</p> <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u></p>	<p><u>Sample size:</u> N = 15</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Average age = 56.7 years (adult daughters), 70.8 years (spouses)</p>	<p><u>Recruitment strategy:</u> Not explicitly specified</p> <p><u>Location:</u> Not explicitly specified</p>	<p><u>Data collection:</u> Interviews</p> <p>Participants completed three interviews each scheduled 30 days apart. Interviews lasted 90 to 135 minutes and all took place</p>	<p>Six themes related to communication emerged from the family members' narratives representing six desired patterns of communication represented by the acronym TALKKK:</p>

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Author, year of publication, country of origin and quality checklist score	Aims, research questions and topics covered or dependent and independent variables	Sample size, participant details: gender, age, ethnicity and relationship to person with dementia	Recruitment strategy and location	Data collection and data analysis	Key findings
<p><u>Country of origin:</u> United States of America (USA)</p> <p><u>Quality checklist score:</u> 26/36</p>	<p>-Experiences of caregivers who have placed their relative in a nursing home</p>	<p><u>Gender:</u> Male = 4, Female = 11</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Spouse = 9, Child = 6</p>	<p>No details were provided about the long-term care settings in this study; except that they were nursing homes</p>	<p>in the family member's home except one held at the nursing home</p> <p><u>Data analysis:</u> Heideggerian hermeneutic (interpretative) phenomenology</p>	<p>-<i>Tell</i>: family members desired to be told information about their relative</p> <p>-<i>Ask</i>: family members desired to be asked to share their knowledge of their relative</p> <p>-<i>Listen</i>: family members wanted staff to listen to their concerns and knowledge</p> <p>-<i>Know</i>: families expected staff to get to know their relative</p> <p>-<i>Knowledge</i>: families expected staff to have specialist dementia knowledge</p> <p>-<i>Knowledge to be shared</i>: families expected staff to share their specialist dementia knowledge with them</p>
<p><u>Author:</u> Piechniczek-Buczek, Riordan &amp; Volicer</p> <p><u>Year of publication:</u> 2007</p> <p><u>Country of origin:</u> United States of America (USA)</p> <p><u>Quality checklist score:</u> 28/36</p>	<p><u>Aim:</u> To explore factors involved in successful visitation for family members of people with dementia residing in a dementia special care unit</p> <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u> -Characteristics of a 'good' visit with a family member with dementia -Characteristics of an 'unsuccessful' visit -How the quality of visits can be improved</p>	<p><u>Sample size:</u> N = unclear (minimum 16, maximum 20)</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Not specified</p> <p><u>Gender:</u> Not specified</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Both spouses and adult children. Exact details not explicitly specified</p>	<p><u>Recruitment strategy:</u> Not explicitly specified</p> <p>Staff members from the dementia special care unit identified family members willing to participate</p> <p><u>Location:</u> Not explicitly specified</p> <p>Participants were recruited from a 100-bed dementia special care unit in a Veteran's Administration Hospital. No further details were provided</p>	<p><u>Data collection:</u> Two focus groups were conducted with 8-10 family members participating in each session. Focus groups were facilitated by two of the authors</p> <p><u>Data analysis:</u> Grounded theory</p> <p>Transcripts were examined for emergent patterns and themes that reflected the meaning provided by participants in response to the main questions</p>	<p>Families identified factors that affected their experience during visits to their relatives; grouped into three domains:</p> <p>-<i>Personal domain</i>: this included factors relating to the characteristics of the resident with dementia and their interaction with their relative</p> <p>-<i>Interpersonal domain</i>: this included factors relating to interactions between residents and staff and between family members and staff</p> <p>-<i>Environmental domain</i>: this included factors relating to the characteristics of the visiting space, the effect of other</p>

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Author, year of publication, country of origin and quality checklist score	Aims, research questions and topics covered or dependent and independent variables	Sample size, participant details: gender, age, ethnicity and relationship to person with dementia	Recruitment strategy and location	Data collection and data analysis	Key findings
					resident's presence and the availability of programs for the residents
<p><u>Author:</u> Shields Scott</p> <p><u>Year of publication:</u> 1991</p> <p><u>Country of origin:</u> United States of America (USA)</p> <p><u>Quality checklist score:</u> 7/36</p>	<p><u>Aim:</u> To identify what families expect from nursing staff caring for their relatives with dementia</p> <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u> Not explicitly specified</p>	<p><u>Sample size:</u> N = 26</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Not specified</p> <p><u>Gender:</u> Male = 10, Female = 16</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Spouse = 10, Child = 16</p>	<p><u>Recruitment strategy:</u> Not explicitly specified</p> <p><u>Location:</u> Not explicitly specified</p> <p>No information about the long-term care setting was provided</p>	<p><u>Data collection:</u> Not explicitly specified</p> <p><u>Data analysis:</u> Not explicitly specified.</p>	<p>Both positive and negative accounts were provided in the following areas:</p> <ul style="list-style-type: none"> <li>-Appreciating families' experiences</li> <li>-Understanding families' feelings</li> <li>-Understanding patients' needs</li> <li>-Assuring patients' safety</li> <li>-Caring with skill</li> <li>-Helping families participate in care</li> <li>-Communicating with families</li> </ul>
<p><u>Author:</u> van Zadelhoff, Verbeek, Widdershoven, van Rossum &amp; Abma</p> <p><u>Year of publication:</u> 2011</p> <p><u>Country of origin:</u> The Netherlands</p> <p><u>Quality checklist score:</u></p>	<p><u>Aim:</u> To investigate the experiences of residents with dementia, their family and nursing staff with group living for people with dementia</p> <p><u>Research question:</u> Not explicitly specified</p> <p><u>Topics covered:</u> -Expectations of group home living -Experiences of daily life and activities in the home -Contact and communication among residents, between</p>	<p><u>Sample size:</u> N = 4</p> <p><u>Participant details:</u></p> <p><u>Age:</u> Not specified</p> <p><u>Gender:</u> Not specified</p> <p><u>Ethnicity:</u> Not specified</p> <p><u>Relationship to person with dementia:</u> Not specified</p>	<p><u>Recruitment strategy:</u> Not explicitly specified</p> <p><u>Location:</u> Southern Netherlands</p> <p>Participants were recruited from two group living units located on the grounds of a traditional large-scale nursing home in an urban area. Each unit housed 10 residents with dementia who all required nursing level care. Residents either had their own room or shared</p>	<p><u>Data collection:</u> Participant observations and interviews</p> <p>Observations followed family members in different situations and held informal conversations with them</p> <p>In-depth interviews lasting approximately 1 hour were conducted. Interviews began with an open question</p>	<p>Four important themes emerged for family members:</p> <ul style="list-style-type: none"> <li>-<i>Being part of:</i> related to how involved family members felt in the group life</li> <li>-<i>Taking responsibility:</i> related to how much responsibility family members took for their relatives</li> <li>-<i>Personalised attention:</i> related to the amount of time family members felt that staff had to spend time with their relative</li> </ul>



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33/36	staff and residents, and between family members and residents -Relations between family members and residents -Possibility to continue family habits and rituals -Possibility to hold on to former identity (personhood)		with another person. Nursing staff worked in day and night shifts. Staff performed household activities with the residents and organised various activities. A multidisciplinary team were involved on a consultation basis	<u>Data analysis:</u> Not explicitly specified  Transcripts were analysed by open coding focusing on recurring themes. Data were analysed by two researchers who discussed different themes and interpretations	- <i>Well-being</i> : related to family members' perceptions regarding the well-being of their relative

### **3.5.2. Aim**

The studies reviewed had different aims. Some focused more generally on families' experiences of care provision (Ejaz, Noelker, Schur, Whitlatch & Looman, 2002; Bramble, Moyle & McAllister, 2009; Mullin, Simpson & Froggatt, 2011; van Zadelhoff, Verbeek, Widdershoven, van Rossum & Abma, 2011); while others focused on specific aspects such as the visiting experience (Piechniczek-Buczek, Riordan & Volicer, 2007). In studies with a particular focus some relevant staff factors may have been overlooked. Furthermore, factors identified as contributing to families' satisfaction may be unique to those specific situations studied rather than their overall satisfaction with care provision.

### **3.5.3. Context**

The majority of studies were conducted in North America; with three in Australia (Bramble, et al., 2009; Edvardsson, Fetherstonhaugh & Nay, 2010; Moyle et al., 2014) and three in Europe (Hertzberg & Ekman, 2000; Mullin et al., 2011; van Zadelhoff et al., 2011). Only one study was conducted in the UK (Mullin et al., 2011). Therefore, there were likely differences in funding arrangements, type of care setting, staff makeup and style of care provision across studies (Table 1.3 outlines this information where available). However, it was not possible to distinguish between these due to a lack of contextual background information in most studies which limits the transferability of the findings.

### **3.5.4. Sample**

Sample sizes were typically small across the studies reviewed. Ten studies incorporated 20 participants or less, with four larger studies incorporating up to 179 participants (Duncan & Morgan, 1994; Ejaz, et al., 2002; Looman, Noelker, Schur, Whitlatch & Ejaz, 1997; Shields

Scott, 1991). In one study the number of participants was unclear (Piechniczek-Buczek et al., 2007). Several studies provided inadequate participant demographic information (Bramble et al., 2009; Edvardsson et al., 2010; MacDonald, 2006; Piechniczek-Buczek et al., 2007; van Zadelhoff et al., 2011); making it difficult to determine whether the sample was representative of the population. Furthermore, in studies which incorporated different family members (e.g. spouses, children), no distinction was made between these in the results.

### **3.5.5. Recruitment**

The majority of studies used convenience sampling. However, four studies did not report sampling information (Looman et al., 1997; Palmer, 2012; Shields Scott, 1991; van Zadelhoff et al., 2011). A reliance on purposive or convenience sampling increases the likelihood that some samples were not representative of the wider population which limits the generalisability of the findings.

### **3.5.6. Ethical Considerations**

Over half of the studies did not mention ethical issues. Whilst three studies demonstrated this (Legault & Ducharme, 2009; Mullin et al., 2011; van Zadelhoff et al., 2011); a further four only demonstrated partial consideration (Bramble et al., 2009; Edvardsson et al., 2010; Moyle et al., 2014; Piechniczek-Buczek et al., 2007). Given the topics researched ethical issues such as informed consent and debriefing seem particularly important. It is unclear whether these studies did not consider ethical issues or whether their consideration was not reported.

### **3.5.7. Method**

One study employed quantitative methodology (Ejaz et al., 2002) whilst the remainder used qualitative methodologies. Rationale for the choice of methodology and evidence of considering alternatives was not always provided. Whilst the majority gave a clear description of the data collection process, others did not (Duncan & Morgan, 1994; Legault & Ducharme, 2009; MacDonald 2006; Piechniczek-Buszek et al., 2007; Shields Scott, 1991 & van Zadelhoff et al., 2011). In those cases it was unclear whether standard procedures were followed and auditing or replicating the data collection would not be possible.

### **3.5.8. Method of Analysis**

The majority of studies provided a clear description of the analysis employed (Bramble et al., 2009; Edvardsson et al., 2010; Ejaz et al., 2002; Hertzberg & Ekman, 2000; Looman et al, 1997; Moyle et al., 2014; Mullin et al., 2011 & Palmer, 2012). However, appropriate justification and theoretical rationale for this was often lacking. Additionally, in the majority of the qualitative studies it was unclear whether themes were endorsed by all participants or just a minority. These omissions could highlight weaknesses in the analyses conducted.

## **3.6. Analysis**

Studies were read in full to identify their main characteristics. The results were summarised and compared to identify recurring staff factor themes which were clustered according to their overarching topic.

#### **4. Results**

Staff factors thought to contribute to families' satisfaction with ongoing care provision were divided into three themes and eight subthemes (see Figure 1.2) which are presented and discussed in turn. For clarity, references to "families" refer to family members of PwD and references to "clients" relate to PwD themselves.

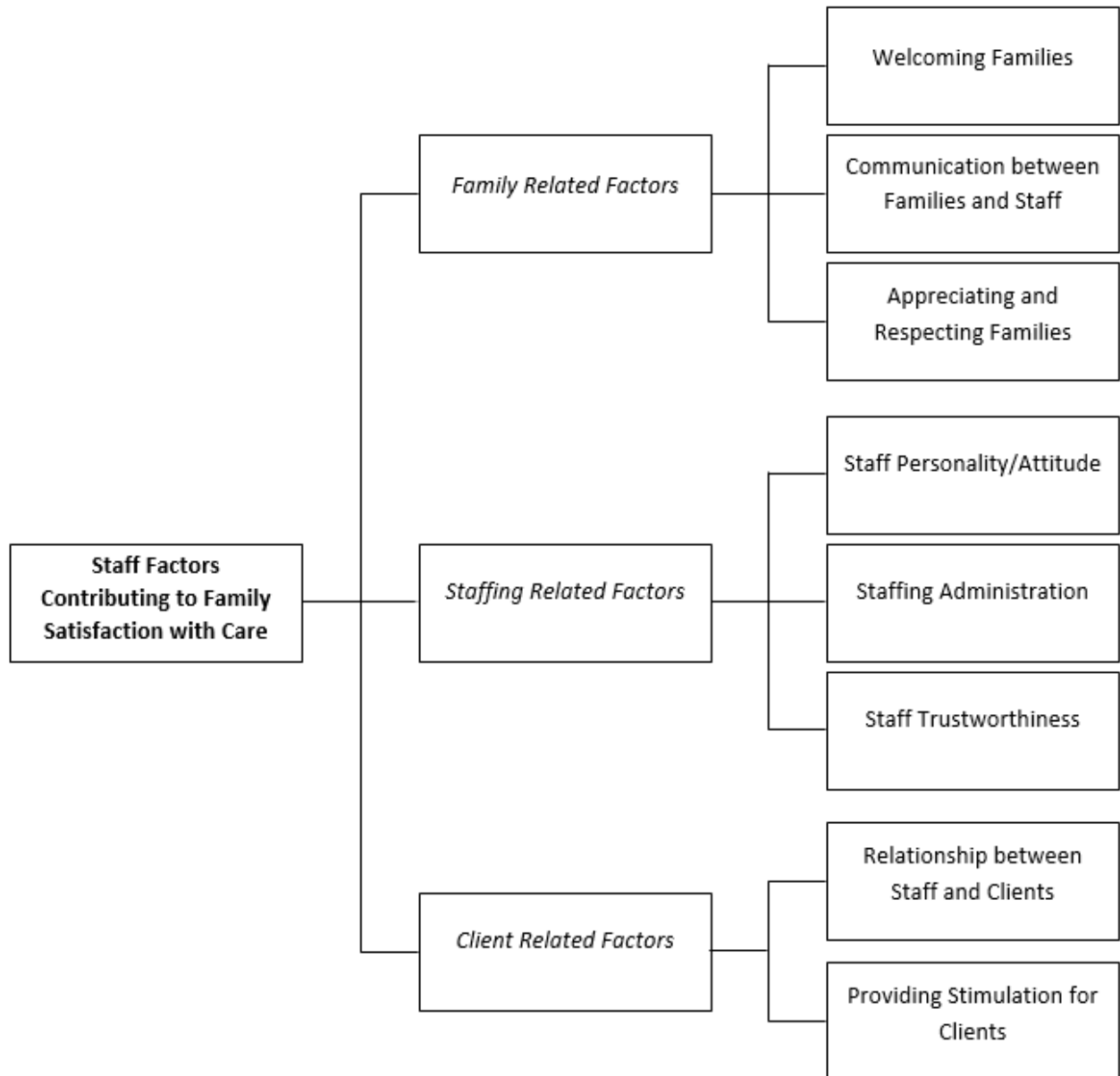


Figure 1.2: Staff Factors Contributing to Family Satisfaction with Care Provision

#### **4.1. Family Related Factors**

The first theme identified related to staff interactions with families; divided into three sub-themes: welcoming families, communication between staff and families, and appreciating or respecting families.

##### **4.1.1. Welcoming Families**

Being welcomed into the life and care of PwD was described as a central element to person-centred care (Edvardsson et al., 2010). Families wanted to participate in care (Bramble et al., 2009; Legault & Ducharme, 2009) and to be included in care planning (Shields Scott, 1991). They appreciated staff encouraging them to share care responsibilities (van Zadelhoff et al., 2011) and to maintain their relationship with their relative (Edvardsson et al., 2010). Being asked their opinions and participating in tasks helped families feel welcomed (Hertzberg & Ekman, 2000). Indeed, families in one study noted the pleasant atmosphere in which they were treated as home members rather than visitors (van Zadelhoff et al., 2011).

Nevertheless, some families felt that staff had not encouraged their involvement (Bramble et al., 2009) whilst others felt that staff were communicating that they should not interfere (Hertzberg & Ekman, 2000). Families wanted an appointed time to talk to staff but often found this request ignored due to lack of time or a suitable environment (Hertzberg & Ekman, 2000). Whilst in general families wanted their participation to be encouraged; in one study some described that being considered as more than just a visitor was too burdensome (van Zadelhoff et al., 2011).

#### **4.1.2 Communication between Families and Staff**

Families wanted to develop ongoing relationships with staff which included staff sharing information and recognising family members' knowledge and experience (Duncan & Morgan, 1994; Legault & Ducharme, 2009; Palmer, 2012). Indeed, developing a relationship of reciprocity was considered crucial to enable families to ask questions, share knowledge and raise concerns or suggestions (Legault & Ducharme, 2009). Families described the quality of their initial contact with staff as crucial for the relationship to take root and develop (Legault & Ducharme, 2009). They reported wanting to establish relationships with staff in order to encourage high quality care (Duncan & Morgan, 1994).

Families valued effective communication (Piechniczek-Buczek et al., 2007); which was seemingly related to their satisfaction (Mullin et al., 2011). They spoke positively about staff being forthcoming with information rather than having to seek this out themselves (Edvardsson et al., 2010); however they did not always find information easy to obtain (Hertzberg & Ekman, 2000). Indeed, families commented negatively about communication if not informed of changes or problems (Shields Scott, 1991). Receiving conflicting reports made them lose confidence in staff and poor communication led to feelings of anger and frustration (Piechniczek-Buczek et al., 2007).

Furthermore, families wanted staff to share their specialist knowledge about caring for their relative (Palmer, 2012). However, some reported receiving inaccurate or insufficient information (Hertzberg & Ekman, 2000). In one study families described a desire to build understanding with staff and wanted a more communicative relationship (Bramble et al., 2009). Although families expressed that working with staff on practical tasks had improved their communication, they described such occurrences as rare (Hertzberg & Ekman, 2000).



#### **4.1.3. Appreciating and Respecting Families**

Families wanted staff to appreciate and respect their experience and to attempt to understand their feelings (Shields Scott, 1991). They appreciated staff attempts to validate their experiences and provide reassurance (Duncan & Morgan, 1994) but did not appreciate negative comments about choices they had made for their relative (Shields Scott, 1991). Some families described wanting emotional support from staff (Shields Scott, 1991) whilst others already felt supported which exceeded their expectations (Looman et al., 1997).

Families wanted staff to listen to their questions, requests or concerns (Legault & Ducharme, 2009; Palmer, 2012). Staff responsiveness was taken as an indication of whether families were taken seriously, with families wanting concrete action rather than mere appeasement from staff (Legault & Ducharme, 2009). Families were concerned that criticising care would lead to no action or their relative being given less attention (Hertzberg & Ekman, 2000). They described situations whereby the staff's reaction to their actions or questions left them feeling embarrassed or belittled (Hertzberg & Ekman, 2000). Indeed, more than 40% of families in one study believed that improvement was needed in how staff handled concerns or complaints (Ejaz et al., 2002).

Families wanted staff to value their extensive experience with their relative (Duncan & Morgan, 1994) and wished to share their knowledge (Legault & Ducharme, 2009; Palmer, 2012). Staff taking their opinions seriously was of utmost importance as they wanted their narratives taken into account when providing care (Hertzberg & Ekman, 2000). Indeed, families expressed frustration if staff appeared reluctant to implement their recommendations (Piechniczek-Buczek et al., 2007). However, some reported that only a

minority of staff demonstrated interest in learning about their relative (Hertzberg & Ekman, 2000).

Families wanted staff to recognise them by name (Duncan & Morgan, 1994) and to take time to talk or share a cup of tea (Edvardsson et al., 2010; Hertzberg & Ekman, 2000). Some had very little staff contact and felt their involvement was not encouraged (Bramble et al., 2009). Not being taken into account made them feel neglected; and some stated that they were never contacted or only contacted in negative situations (Hertzberg & Ekman, 2000). Indeed, in one study families who perceived significant improvements were needed in care provision had more negative interactions with staff (Ejaz et al., 2002).

#### **4.2. Staffing Related Factors**

The second theme identified related to families' staffing expectations; divided into three sub-themes: staff personality/attitude, staffing administration and staff trustworthiness.

##### **4.2.1. Staff Personality/Attitude**

Families in one study described staff as kind, attentive, friendly and approachable; which contributed to their overall satisfaction (Mullin et al., 2011). Families valued the genuine warmth and caring staff expressed (Looman et al., 1997) and wanted staff to relate to their relative in a professional and respectful manner (Duncan & Morgan, 1994). Staff demonstrating respect, kindness and their interest in and familiarity with clients was deemed important (Legault & Ducharme, 2009). Furthermore, families in a further study valued the staff approach; described as "based on respect for personhood, with warmth, trust, openness, hospitality, care and honesty, both in contact with residents and family members" (van Zadelhoff et al., 2011, p.2495).

However, some families noted the inflexible attitude of some staff (MacDonald, 2006). Indeed, in another study, families felt that significant improvements were needed when care was not perceived to be sensitive (Ejaz et al., 2002). Some families monitored staff attitude to ensure it was sensitive to their relative's needs (Duncan & Morgan, 1994). Nevertheless, this was not universal, as in a further study families expressed satisfaction with staff attitude and friendliness (Bramble et al., 2009).

Furthermore, families highlighted the importance of staff prioritising clients over tasks in order to demonstrate a person-centred approach (Edvardsson et al., 2010). Whilst this was considered crucial; some families experienced staff caring for their relatives in their free time which exceeded their expectations (Looman et al., 1997).

#### **4.2.2. Staffing Administration**

Families highlighted the importance of adequate staffing, in particular for ensuring clients had ample stimulation and attention (Piechniczek-Buczek et al., 2007). However, on occasion families felt staffing was inadequate (Mullin et al., 2011) and some cited this as a reason why they felt the care was insufficient (Hertzberg & Ekman, 2000). Furthermore, families highlighted concerns about the consequences of insufficient staff such as increased agitation (MacDonald, 2006). They also felt it contributed to inadequate one-on-one time and reduced opportunities for learning about clients' past interests (MacDonald, 2006). Families felt there were insufficient staff to reassure them and although mindful of low staffing levels, wanted one staff contact point (Bramble et al., 2009). In a further study families understood the challenges under-staffing presents, but nevertheless commented negatively about its impact on care provision (Looman et al., 1997).

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Families described that in order to develop the trust and relationships with staff that are required for person-centred care, low staff turnover and consistent staffing was needed (Edvardsson et al., 2010). Indeed, they described the lack of consistent staff as inadequate (Mullin et al., 2011) and commented negatively about high staff turnover (Looman et al., 1997); expressing that some staff knew almost nothing about their relative (Hertzberg & Ekman, 2000). Additionally, families reported feeling exhausted by regularly having to start relationships with new staff (Hertzberg & Ekman, 2000).

Families described that staff had to be available and present in order to be person-centred (Edvardsson et al., 2010). However, more than 40% of families in one study felt that improvements were needed in the amount of care provided (Ejaz et al., 2002). In another study families felt that management did not prioritise staff spending time with clients (Moyle et al., 2014). Furthermore, they described that person-centred care should incorporate flexible routines adapted to their relative's needs rather than the needs of the organisation or staff (Edvardsson et al., 2010).

Families reported inexperienced staff as a concern meaning that the care was inadequate (Mullin et al., 2011). Families in one study cited insufficiently educated staff as one of the reasons why they felt the care was not sufficient (Hertzberg & Ekman, 2000). In another study families expressed that staff had **insufficient time for education and felt** that increasing their dementia knowledge would improve care provision (MacDonald, 2006). Indeed, staff being knowledgeable about dementia was considered important to enable communication with families regarding disease progression (Palmer, 2012).

### **4.2.3. Staff Trustworthiness**

Families placed great importance on their ability to trust staff and expected the quality of care to be on par with what they themselves would provide (MacDonald, 2006). A positive evaluation of care provision was associated with the development of trust; with a lack of trust resulting in families carrying out heightened supervision of staff (Legault & Ducharme, 2009). For example, some paid particular attention to how their relative reacted to staff (Duncan & Morgan, 1994); whilst others monitored how staff treated other clients since they expected staff to treat their relative well during their visit (Duncan & Morgan, 1994). Families in one study reported ongoing care scrutiny; suggesting that without monitoring appropriate care may not be provided (Mullin et al., 2011).

## **4.3 Client Related Factors**

The third theme identified related to how staff related to clients; divided into two sub-themes: the relationship between staff and clients and the provision of stimulation.

### **4.3.1. Relationship between Staff and Clients**

The relationship staff developed with clients appeared to contribute to families' satisfaction. Indeed, it was highlighted that despite other factors being important, "ultimately, it was the quality of the care that staff delivered to the resident that mattered most" (Duncan & Morgan, 1994, pp.240-241). In one study families identified kin-like relationships between their relatives and staff and appreciated staff seeing clients as family members (Looman et al., 1997). Families indicated the importance of their relatives being treated as unique individuals; more than just objects requiring care (Duncan & Morgan, 1994; Looman et al., 1997). Indeed, families expressed that they would search for better quality care if staff treated

their relatives as part of the workload rather than relating to them as a person (Duncan & Morgan, 1994).

Families looked for emotional connections to develop between their relative and staff (Palmer, 2012); viewing this as evidence that their relatives were being treated with care and respect (Piechniczek-Buczek et al., 2007). Staff being on familiar terms with clients and demonstrating kindness and respect heightened families' trust in staff (Legault & Ducharme, 2009). Indeed, families felt relieved when their relative became attached to staff as they assumed this indicated that appropriate care was being provided (Piechniczek-Buczek et al., 2007). In contrast, families in one study felt their relative wearing someone else's clothes may reflect staff not connecting with them in a meaningful way (Bramble et al., 2009).

Families appreciated staff relating to their relatives as unique individuals with a specific history and individual qualities (van Zadelhoff et al., 2011; Looman et al., 1997). They expected staff to know their relative's needs, routines and habits; reporting that respecting their relative's personhood was important (Palmer, 2012). Indeed, families described that person-centred care included staff being aware of their relative's history and supporting them to be who they were before diagnosis (Edvardsson et al., 2010).

Families wanted staff to relate to their relatives in a manner which reflected an understanding of their preferences and preserved their dignity (Looman et al., 1997; van Zadelhoff et al., 2011). Indeed, families did not want their relative's need for care to impact negatively on their dignity and worth (Duncan & Morgan, 1994); reporting that observing staff respecting their relative's needs for privacy and dignity was particularly reassuring (Piechniczek-Buczek et al., 2007). Furthermore, families wanted staff to recognise and respond to their relative's moods and behaviours (Palmer, 2012).

#### **4.3.2. Providing Stimulation for Clients**

Providing meaningful activities and allowing clients to make decisions were seen as essential components of person-centred care (Edvardsson et al., 2010). Families wanted staff to provide opportunities and activities tailored to their relative's likes; describing that this indicated that staff valued them (Mullin et al., 2014). Involving clients in activities adapted to their ability level in order to foster their self-esteem was also considered important (Edvardsson et al., 2010). Additionally, families wanted their relatives to have opportunities for social engagement (Mullin et al., 2014; Piechniczek-Buczek et al., 2007) including support to participate in parties and celebrations (Edvardsson et al., 2010). Families in one study reported that observing their relative's involvement in activities gave them a sense of relief and gratification (Piechniczek-Buczek et al., 2007).

Families reported mixed experiences regarding activity provision. For some, activities were a positive aspect of the care contributing to their satisfaction, whilst others had concerns about the lack of stimulation for their relative (Mullin et al., 2011). In a further study 43% of families felt that improvements were needed in the variety of activities provided and 48% felt improvements were needed in the amount of personalised attention given to clients (Ejaz et al., 2002). Furthermore, families in another study were frustrated by the lack of client involvement in activities (Piechniczek-Buczek et al., 2007).

### **5. Discussion**

The present systematic review explored staff factors that appear to contribute towards families' satisfaction with ongoing care provision for their relatives with dementia in long-term care. Staff factors were identified in three broad areas: family-related factors, focusing

predominantly on staff interaction with families; staffing related factors, focusing on staffing organisation and composition; and client related factors, focusing on staff interaction with clients. These findings build on and extend findings from previous reviews which focussed more specifically on family experiences at points of transition (Hennings et al., 2010; Graneheim et al., 2014).

Whilst there was broad consensus about the three main areas that seemed to contribute to families' satisfaction, there were differences in exactly what families considered important. This may be accounted for by individual differences between participants in the studies reviewed or these differences may have arisen due to the different study aims and the particular questions families were asked about their experiences.

### **5.1. Clinical Implications**

Given that families' satisfaction was related to more than just staff interaction with their relatives, it is important that these additional staff factors are considered. For example, it appeared that staff interaction with families themselves and staffing related factors also contributed to families' overall satisfaction. This has important implications for care home managers and staff working with PwD in long-term care settings.

The findings indicate that several factors should be considered when planning staffing in long-term care settings for PwD. For example, families expressed concerns about staffing levels, staff consistency, knowledge and attitude; both in relation to clients and families themselves. This has implications for shift organisation and for staff training, recruitment and retention. Families wanted knowledgeable staff who were responsive to their relative's needs and also their needs as family members. This indicates that staff training in long-term care settings for



PwD should focus not only on staff education but also on establishing effective relationships with both clients and families.

It has been recognised that when staff are appropriately educated, trained and supported this not only benefits PwD through higher quality care promoting dignity and compassion, but also provides greater reward for staff leading to lower staff turnover and greater continuity of care (DOH, 2015). Therefore, improving staff training may directly contribute towards families' satisfaction in terms of the overall quality of care provision, and also indirectly lead to greater consistency in staffing which appears to be another important factor contributing to their overall satisfaction. Furthermore, clinical supervision may improve staff interactions with clients and families as it has been highlighted that it "can help ensure that people who use services and their carers receive high quality care at all times from staff who are able to manage the personal and emotional impact of their practice" (Care Quality Commission, 2013a, p.5).

The findings suggest that staff working with PwD in long-term care settings should not only be mindful of their relationships with clients but also their ongoing relationships with families. **Families want reciprocal relationships** with staff in which they can ask questions, raise concerns and share their knowledge. **They expect staff to value** their perspective by demonstrating an interest and seeking out information as well as spontaneously offering support and advice. Indeed, relationship-centred care emphasises the central importance of the interaction between clients, families and staff. Models of relationship-centred care (e.g. Nolan et al., 2006) emphasise the importance of improving care through a relationship-centred approach involving families as well as staff and clients. Arguably such models could

usefully inform staff training directed at fostering best practice by encouraging staff to recognise the importance of their relationship with families.

- Families want knowledgeable staff who are responsive to their relative's needs as well as their own needs as family members
- Staff training should not only focus on staff education but also on establishing effective relationships with both clients and families
- Improved staff training may directly contribute to families' satisfaction by improving the quality of care provision and indirectly by leading to greater consistency in staffing

## **5.2. Limitations**

Only studies published in English were included in the present review which could have limited the overall findings. A specific type of long-term care setting was not specified. Therefore, studies included the perceptions of family members of PwD who resided in a range of different long-term care settings which limits the conclusions that can be drawn. Studies generally did not provide clear descriptions of the type of care setting, level of care and staffing levels provided. It is possible that these factors may have influenced families' perceptions; however this was not possible to determine due to the lack of contextual information available. It would be helpful for future studies to identify the nature of the care provided to enable this to be explored.

Family experiences were categorised as those from any close family member. However, generally responses were not differentiated meaning it was not possible to consider

similarities or differences between, for example, spouses and adult children. The majority of studies incorporated adult children as participants; a sampling bias which may have influenced the results since different staff factors may contribute to the satisfaction of family members with different relationships to PwD. Although one study incorporated only spouses (Mullin et al, 2011); there were no differences in the staff factors which arose from this study compared to the studies which also incorporated adult children. We therefore have no evidence to suggest that there is a difference between the staff factors that contribute to satisfaction between spouses and adult children; however this could be a topic for further research. Additionally, the studies reviewed had some methodological weaknesses previously highlighted which limit the generalisability of the findings.

### **5.3. Future Research Directions**

This review highlighted the limited research focussing explicitly on families' overall perceptions of ongoing care provision for PwD in long-term care; and in particular the paucity of research explicitly focussing on relevant staff factors contributing to families' satisfaction. Much of the literature reviewed here focused on specific aspects of care provision, such as families' perceptions of their relative's leisure opportunities or their relationships with staff. There is a need for further research focusing more explicitly on families' overall perceptions of care provision for PwD in long-term care and for research directly investigating staff factors contributing to families' satisfaction. Consistent with a relationship-centred model it would also be interesting to obtain similar data from staff about the family factors which may contribute towards their satisfaction with providing care.

Further research could address the methodological weaknesses present in the studies reviewed. For example, the majority of studies incorporated small samples and therefore

larger scale studies would strengthen the generalisability of study findings. Given the predominance of convenience sampling in the studies reviewed, the use of purposive sampling would also strengthen the design of future studies. Further research may also be improved by considering ethical issues, differentiating the responses of participants with different relationships to PwD and by providing clear descriptions of the study context.

#### **5.4. Summary and Conclusion**

Given the lack of clarity regarding staff factors contributing towards families' overall satisfaction with ongoing care provision for PwD in long-term care, this review aimed to critically evaluate existing empirical literature in this area. The findings highlighted staff factors in three broad areas which appeared to contribute to families' satisfaction: family related factors, staffing related factors and client related factors.

Regarding family related factors, families wanted to be welcomed into the life and care of their relative and wished for a reciprocal relationship with staff, with good communication, appreciation and respect. In relation to staffing related factors, families had particular expectations regarding staff attitude. They wanted staff to prioritise clients over tasks and to be able to trust staff to provide high quality care. Furthermore, families wanted well-educated staff, adequate staffing levels and consistent staffing. Regarding client related factors, families wanted staff to establish a connection with their relative, to provide stimulation and to be responsive to their relative's individual needs.

These findings have important clinical implications for staff working with PwD in long-term care settings. Further research focusing more explicitly on the staff factors contributing to families' overall satisfaction with care provision is needed in order to corroborate and extend

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the findings presented here. However, given the importance of family satisfaction with the care of PwD, these findings provide insight into the main staff factors which may contribute towards this. Furthermore, these findings highlight areas for improvement which may ultimately improve the overall quality of care for PwD in long-term care settings.

## **6. Declaration of Conflicting Interests**

The authors declare that there is no conflict of interest.

## **7. Funding Acknowledgement**

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

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