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Author

Pu, Lihui, Chen, Hongxiu, Jones, Cindy, Moyle, Wendy

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**Family Involvement in Pain Management for People Living with Dementia:  
An Integrative Review**

Lihui Pu, PhD, MSN  
Postdoctoral Research Fellow  
Menzies Health Institute Queensland & School of Nursing and Midwifery  
Griffith University  
170 Kessels Road, Nathan Queensland 4111, Australia  
Phone: 61 7 3735 7212  
Email: [l.pu@griffith.edu.au](mailto:l.pu@griffith.edu.au)  
<https://orcid.org/0000-0003-0136-0940>

Hongxiu Chen, MSN  
West China School of Nursing, Sichuan University/Innovation Center of Nursing Research,  
Nursing Key Laboratory of Sichuan Province, West China Hospital, Sichuan University  
No.37 Guo Xue Street, Chengdu, Sichuan Province, P.R. China 610041  
Phone: +8317313149018  
Email: [chenhongxiu@stu.scu.edu.cn](mailto:chenhongxiu@stu.scu.edu.cn)  
<https://orcid.org/0000-0001-8235-5646>

Cindy Jones PhD, BA (Psych), BB (HRM)  
Associate Professor, Faculty of Health Sciences & Medicine  
Bond University  
14 University Drive, Robina, Queensland 4226, Australia  
Phone: +61 7 5595 1152 |  
Email: [cjones@bond.edu.au](mailto:cjones@bond.edu.au)  
<https://orcid.org/0000-0002-7249-2580>

Wendy Moyle PhD, MHSc, BN, DipAppSci, RN  
Program Director & Professor  
Menzies Health Institute Queensland & School of Nursing and Midwifery  
Griffith University  
Brisbane, Australia  
170 Kessels Road, Nathan Queensland 4111, Australia  
Phone: +61 7 373 5526 |  
Email: [w.moyle@griffith.edu.au](mailto:w.moyle@griffith.edu.au)  
<https://orcid.org/0000-0003-3004-9019>

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## Author Biographical Paragraphs

**Lihui Pu, PhD, MSN**, is a Postdoctoral Research Fellow working in the Menzies Health Institute Queensland, Griffith University. Her work focuses on using innovative technologies to support older people, particularly people with dementia and chronic pain. Recent publications include:

Pu, L., Coppieters, M., Byrnes, J., Jones, C., Smalbrugge, M., Todorovic, M., & Moyle, W. (2022). Feasibility study protocol of the PainChek app to assess the efficacy of a social robot intervention for people with dementia. *Journal of Advanced Nursing*, 78(2), 587-594. <https://doi.org/10.1111/jan.15106>

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**Hongxiu Chen, MSN**, is doctoral student in West China School of Nursing, Sichuan University/ Innovation Center of Nursing Research, Nursing Key Laboratory of Sichuan Province, West China Hospital, Sichuan University. Her work focuses on the competency development of geriatric nurses. Recent publications include:

Chen, H., Pu, L., Chen, Q., Xu, X., Bai, C., & Hu, X. (2019). Instrument development for evaluation of gerontological nurse specialists core competencies in China. *Clinical Nurse Specialist*, 33(5), 217-227. <https://doi.org/10.1097/NUR.0000000000000469>

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**Cindy Jones, BA (Psych), BB (HRM)**, is an associate professor of Behavioural Science in the Faculty of Health Sciences and Medicine at Bond University. Her research expertise includes social and behavioral science research relating to older people particularly people with dementia, technology use to enhance care provision and care outcomes as well as workforce training and development. Recent publications include:

Jones, C., Moyle, W., & Van Haitsma, K. (2021). Development of the ‘Intimacy and Sexuality Expression Preference’ tool for residential aged care. *Geriatric Nursing*, 42(4), 825-827. <https://doi.org/10.1016/j.gerinurse.2021.04.004>

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**Wendy Moyle, PhD, MHSc, BN, DipAppSci, RN**, is Program Director in the Menzies Health Institute Queensland, Griffith University, Australia and Professor in the School of Nursing. Her research expertise is focused on older people and includes technology use and evaluation in people with dementia, depression, delirium, and family carers. Her recent publications include:

Moyle, W., Murfield, J., & Lion, K. (2022). Therapeutic use of the humanoid robot, Telenoid, with older adults: A critical interpretive synthesis review. *Assistive Technology*. Advance online publication. <https://doi.org/10.1080/10400435.2022.2060375>

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Moyle, W., Murfield, J., & Lion, K. (2021). The effectiveness of smart home technologies to support the health outcomes of community-dwelling older adults living with dementia: A scoping review. *International Journal of Medical Informatics*, 153, 104513. <https://doi.org/10.1016/j.ijmedinf.2021.104513>

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**Address all correspondence to:** Lihui Pu, PhD, MSN, Postdoctoral Research Fellow, Menzies Health Institute Queensland & School of Nursing and Midwifery, Griffith University, 170 Kessels Road, Nathan Queensland 4111, Australia; Email: [l.pu@griffith.edu.au](mailto:l.pu@griffith.edu.au)

### **Abstract**

This review aimed to synthesize current evidence on family involvement in pain management for people living with dementia from the perceptions of family carers and healthcare professionals. An integrative review was conducted using CINAHL, Embase, PubMed, PsycINFO and Cochrane Library electronic databases. The Mixed Methods Appraisal Tool was used to appraise the articles, followed by thematic analysis. Twelve studies were included and four themes were identified: (1) The roles and responsibilities of family carers; (2) Enablers and barriers for pain identification; (3) Strategies and concerns for pain management; and (4) Lack of staff education and communication with healthcare providers. Family carers play an important role in pain assessment and management for people living with dementia, but they cannot be actively involved in this process due to a lack of communication with healthcare providers. An integrated approach that includes education and communication with family carers and healthcare providers is needed.

Pain management is suboptimal for people with dementia regardless of pain medication use (Bullock et al., 2021; La Frenais et al., 2021). It is estimated that around half the older people with dementia living in nursing homes experience pain (van Kooten et al., 2017), and a similar percentage for those in acute care settings (Feast et al., 2018) and communities (Bullock et al., 2019). The reduced ability for people with dementia to report and communicate their pain experience is a challenge for formal and informal carers. In addition, it is widely accepted that people with dementia are under-recognized and under-treated for pain (Achterberg et al., 2021; Giménez-Llort et al., 2020), leading to behavioral and psychological symptoms in people living with dementia (Boltz et al., 2021; Wei et al., 2021) and the use of psychotropic medications (Nowak et al., 2018). This can also increase healthcare providers' and family carers' care burden (Guliani et al., 2021; Regier et al., 2021).

Pain management is one of the most identified care burdens family carers face, particularly in end-of-life caregiving for people with advanced dementia (Malhotra et al., 2021). Families often report negative emotional responses, such as helplessness and anxiety, when people living with dementia are experiencing pain (Malhotra et al., 2021). Pain management for relatives is an expressed concern. Family carers encounter many challenges such as pain identification and communication, misunderstanding of pain medication administration, and poor communication with care providers (Chi et al., 2018). However, families express their willingness to collaborate with healthcare providers to manage better pain (Riffin et al., 2022). As pain behaviors differ between individuals living with dementia, pain assessment should include insights from family carers to interpret the meaning of pain behaviors (The British Pain Society, 2018). Moreover, healthcare providers acknowledge the family's crucial roles in pain assessment and management for older people with dementia (Fry et al., 2017). Adequate pain relief and better communication between families and

healthcare providers can significantly positively impact people with dementia and alleviate the care burden.

Families play a key role in delivering care and support services for pain management in people living with dementia. However, despite policy initiatives recommending that partnerships with family carers could achieve high quality and sustainable care (Department of Health Social Care, 2018; Häikiö et al., 2020), limited guidance and research are available on how families of people living with dementia can be involved in their pain management. Furthermore, families' expertise is often not recognized. As a result, families are repeatedly excluded from knowledge exchange, care planning, and decision-making regarding pain management (Lundin & Godskesen, 2021). As a result, there remains much to be understood about the involvement of family carers in pain management for people living with dementia.

Previous review studies on family involvement for pain management in people living with dementia primarily focused on comparing pain ratings by the patient and family carers (Kankkunen & Välimäki, 2014) and pain management in end-of-life care (Chi et al., 2018). As a result, an understanding of the challenges and needs of pain management, specifically for family carers, is limited. To address this gap, this study aims to synthesize current scientific evidence on family involvement in pain management for people living with dementia from the perceptions of family carers and healthcare professionals. Study findings will inform the development of interventions for family involvement to improve pain management and care quality for people living with dementia.

## **Method**

### **Protocol and Registration**

This review was registered on the PROSPERO International Prospective Register of Systematic Reviews (registration number: CRD42021227378).

### **Review Question**

What are the perceptions of family carers and healthcare professionals in relation to family roles and their involvement in the pain management of people living with dementia?

### **Design**

This review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009). The PRISMA reporting checklist was used to report the identification, selection, appraisal and synthesis of the articles in this review (this can be found in a Supplementary file 1). Moreover, the Whitemore and Knafl's integrative review methodology (Whitemore & Knafl, 2005) was used to permit the inclusion of all research designs, including experimental and non-experimental studies.

### **Search Methods**

Five English databases (CINAHL, MEDLINE, PubMed, Embase, and PsycINFO) were searched in October 2020 and updated in December 2021. Search terms included synonyms and derivatives of "Caregivers", "Family", "Spouses", "Adult children", "Alzheimer disease", "Dementia", "Cognitive impairment", "Cognition disorders", "Pain", "Pain management", "Analgesia". MESH terms and key terms were used in the title and abstract to increase the search coverage and were combined using Boolean. The search terms were tailored to each database to address the differences in thesaurus terminology and indexing. Our search strategies are reported in Supplementary file 2. The reference lists of reviews pertinent to this research area and the included studies were searched manually.

### **Types of Studies Included**

All qualitative, quantitative and/or mixed methods studies published in English focusing on family involvement in pain management of people living with dementia from perspectives of family carers and healthcare professionals were included. However, studies investigating or developing assessment tools or non-original research such as literature

reviews, theses, newsletters, editorials, commentaries and discussion documents, notes, and conference proceedings were excluded.

### **Study Selection and Data Extraction**

After removing duplicates, screening the titles and abstracts of the studies retrieved during the searches were independently conducted by two authors (LP & HC) according to the inclusion and exclusion criteria. The two authors (LP & HC) then retrieved and assessed the full texts of eligible studies. A table was then used to extract data for eligible studies for data synthesis. The extracted information included: citation; country; study aim; study design; setting; sample; data collection method; and study conclusions. One author (LP) extracted the data, and another (HC) read the articles against the extracted data to identify any discrepancies in extraction. Any disagreements during these processes were resolved by discussion among the authors.

### **Data Analysis**

Inductive thematic analysis and narrative synthesis were undertaken to develop emergent themes from the patterns identified in the chosen studies (Whittemore & Knaf, 2005). The included articles were read, re-read, and coded. Categories were created to compare codes, and the main themes were agreed upon by discussion. This ensured that the themes that emerged from different codes were linked to the data from all the studies included in the analysis. Data was conceptually triangulated to understand family involvement in the pain management of people living with dementia. An integrative synthesis of both qualitative and quantitative studies was undertaken.

### **Methodological Quality Appraisal**

The authors critically appraised the quality of the included studies using the 2018 Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). The MMAT is a valid and reliable critical appraisal tool designed for systematic mixed methods studies (Hong et al.,

2019). To inform the quality of the included studies, MMAT does not require the computation of an overall score from criteria ratings but instead encourages detailed reporting on criteria ratings. Any disagreements that arose were resolved by discussions between the authors where necessary.

## **Results**

### **Results of the Search**

A total of 3547 records were identified from five databases and four records following reference checking. After removing duplicates, 1936 records were screened on titles. Of these, 1761 and 131 citations were excluded based on titles and abstracts, respectively. The remaining 44 full-text studies were then reviewed where 32 studies were excluded based on (a) no family involvement was reported in the study; (b) findings not related to pain management; (c) study theses; and (d) care recipients were without a diagnosis of dementia. As a result, a total of 12 studies that met the inclusion criteria were included in the review. The PRISMA flowchart of study selection is presented in Figure 1.

[Insert Figure 1 about here]

### **Risk of Bias**

A summary of the quality assessment for all studies is presented in Table 1. The overall methodological quality of reviewed studies was robust. All included studies provided a clear statement of aims and appropriate data collection methods to address their research questions. Two quantitative studies were assessed as a potential risk of inappropriate assessment tools selection and low response rate with risk of nonresponse bias (Barry et al., 2015; Buffum & Haberfelde, 2007). The quality of the mixed method study (Corbett et al., 2016) and nine qualitative studies were rated as good quality (Bullock et al., 2020; Falls & Stevens, 2004; Lichtner et al., 2016; Lundin & Godskesen, 2021; Martin et al., 2005; Mentis et al., 2004; Newton et al., 2018; Riffin et al., 2022; Tarter et al., 2016).

[Insert Table 1 here]

### **Description of Included Studies**

Characteristics of the included studies are presented in Table 2. We included 12 studies, the majority of which were based on qualitative methodology ( $n = 9$ ) (Bullock et al., 2020; Falls & Stevens, 2004; Lichtner et al., 2016; Lundin & Godskesen, 2021; Martin et al., 2005; Mentes et al., 2004; Newton et al., 2018; Riffin et al., 2022; Tarter et al., 2016).

Among these included studies, most were conducted in the USA ( $n = 4$ ) (Buffum & Haberfelde, 2007; Mentes et al., 2004; Riffin et al., 2022; Tarter et al., 2016) and the UK ( $n = 4$ ) (Bullock et al., 2020; Corbett et al., 2016; Lichtner et al., 2016; Newton et al., 2018). The remaining four papers were from Sweden, Ireland, Canada, and Australia. Most studies were conducted in long-term care facilities ( $n = 5$ ) (Barry et al., 2015; Corbett et al., 2016; Falls & Stevens, 2004; Lundin & Godskesen, 2021; Mentes et al., 2004) and communities ( $n = 4$ ) (Bullock et al., 2020; Martin et al., 2005; Newton et al., 2018; Riffin et al., 2022). The majority of studies included both family carers and healthcare providers ( $n = 8$ ) (Barry et al., 2015; Bullock et al., 2020; Corbett et al., 2016; Falls & Stevens, 2004; Lichtner et al., 2016; Martin et al., 2005; Mentes et al., 2004; Riffin et al., 2022). The sample size varied from 13 (Lundin & Godskesen, 2021) to 93 (Barry et al., 2015).

[Insert Table 2 about here]

### **Synthesis of Results**

Based on the study results, we identified four themes regarding family involvement in pain management (Table 3), including (1) The roles and responsibilities of family carers; (2) Enablers and barriers for pain identification; (3) Strategies and concerns for pain management; and (4) Lack of staff education and communication with healthcare providers.

[Insert Table 3 about here]

**Theme 1: The Roles and Responsibilities of Family Carers**

A total of five studies highlighted the roles of families where they were responsible for the day-to-day identification, assessment, monitoring, and subsequent pain management in people living with dementia. However, challenges of being actively involved in pain management were reported, including not being heard due to a lack of formal structure and support for communication networks between families and professional care providers. Therefore, a team-based approach involving family carers and care providers was recommended to better manage pain in people living with dementia.

**Theme 2: Enablers and Barriers for Pain Identification**

Families reported the under-identified and thus undertreated pain in people with dementia, leading to people with dementia experiencing pain “most” or “all” of the time. In addition, they identified cognitive and communicative impairments as significant barriers to effective pain identification in people living with dementia. Therefore, three strategies were suggested to support pain assessment for non-verbal people living with dementia. First, care providers should be familiar with the person with dementia in order to provide person-centredness and individualising pain management that in turn builds trust and familiarity. This process also highlighted the importance of identifying individual pain behaviours and the need for consistency of care staff. Second, there is a need to identify different pain signs and symptoms, including facial expressions, behaviours, verbal expressions and body language. Third, regular observation and assessment and day-to-day monitoring were recommended to identify changes in people living with dementia.

**Theme 3: Strategies and Concerns for Pain Management**

Both pharmacological and non-pharmacological methods were identified to manage pain in people living with dementia. Families reported the importance of timely and consistent medication administration but were concerned about pain medication side effects,

such as medication reliance and polypharmacy. This could bring challenges to clinicians, especially when clinicians involve families in the pain management decision-making process, such as the use of opioid analgesics. Furthermore, many non-pharmacological methods were reported to help manage pain experienced by people living with dementia, including distraction, relaxation, massage, re-positioning, music, physical therapy and exercise.

#### **Theme 4: Lack of Staff Education and Communications with Healthcare Providers**

Families generally reported receiving inadequate information about their relatives' medical conditions, including pain experience. Additionally, their knowledge of pain assessment and management were also limited. This situation is exacerbated by the lack of staff education in pain awareness and knowledge of pain management and communication. Therefore, educational interventions were recommended to improve communication and support pain assessment and management for families and healthcare providers. These interventions included increased documentation and communication skills, selecting and using appropriate pain scales and initiating follow-up discussions for better carer-clinician communication.

## **Discussion**

### **Summary of Findings**

This study provides a comprehensive insight into an under-explored area of family involvement in the pain management of people living with dementia. Our study identified the important roles that family carers could play in assessing and managing pain in this group. However, challenges and barriers identified include the cognitive and verbal deficits of people with dementia during pain assessment and management, together with limited correspondence and information from healthcare professionals. Reported strategies used by families that could be used to improve pain assessment and management included being familiar with people living with dementia; regular pain assessment using facial expressions,

behaviours, verbal expressions, and body language; as well as pharmacological and non-pharmacological interventions to relieve pain. An integrated approach with improved communication between families and healthcare providers is recommended for better pain management in people living with dementia.

### **Involving Family Carers in Pain Identification and Management**

Family members were discussed frequently as partners and facilitators in determining residents' comfort levels and promoting comfort. First, they are identified as key advocates for pain identification and management in people living with dementia, especially those with limited communication skills or non-verbal as families are familiar with their behavioural changes indicative of pain (Bullock et al., 2020; Lundin & Godskesen, 2021; Tarter et al., 2016). Second, they are responsible for initiating non-pharmacological and managing medication treatments for people with dementia, particularly in community settings (Bullock et al., 2020; Lichtner et al., 2016). Not only is pain management one of the key aspects of care for people with dementia, but the inability to manage pain can also trigger behavioural changes, functional decline, and falls (van Dalen-Kok et al., 2021; Wei et al., 2021), leading to increased healthcare costs (Guliani et al., 2021). Evidence shows that providing adequate pain management training can improve pain management in patients with hospice care and reduce caregiver burden (Chi et al., 2020). Therefore, enabling and involving families to provide better pain management will benefit both family carers and people with dementia and mitigate the increasing costs of dementia care.

### **Supporting Family Carers in Pain Identification**

Families should be encouraged to assess pain in people with dementia actively. Healthcare professionals acknowledge the assistance family carers provide in the detection and/or assessment of pain for people with cognitive impairment (Lundin & Godskesen, 2021; Riffin et al., 2022). Credible information can be obtained from a family carer who knows the

patient well (e.g., spouse, child, caregiver). Familiarity with the patient and knowledge of usual and past behaviours can also assist in identifying less apparent changes in behaviours that may be indicators of pain presence (Fry et al., 2015; Monroe et al., 2015). It is feasible to improve the assessment and identification of pain in people with dementia through validated tools that family members can use, such as the Pain Assessment in Advanced Dementia tool (PAINAD) (Bentur et al., 2021; Fry & Elliott, 2018). Moreover, judgments by family carers can support healthcare professionals' decision-making with other clinical observations and assessments (Sirsch et al., 2020). Therefore, a multifaceted approach is recommended that combines direct observation, family carer input, and evaluation of response to treatment. Importantly, family carers must be trained in using the validated tools to assess pain.

### **Supporting Family Carers in Pain Management**

Pain management in people living with dementia remains challenging for family carers and healthcare professionals. Both non-pharmacological and pharmacological strategies are recommended to treat pain with families highlighting the importance of non-drug alternatives. The commonly used alternatives such as massage, music, relaxation, and distraction are effective in pain reduction for people with dementia, and they are without serious side effects (Corbett et al., 2016). In addition, the literature supports non-pharmacological interventions can reduce pain in people with dementia (Liao et al., 2021; Pu et al., 2019). Family carers can apply these strategies to provide pain relief, whether at home or in care facilities.

Family involvement in the decision-making of pain medication use is essential, especially the prescription of narcotic analgesics for people living with dementia. Although pain relief medications are the primary treatments to manage pain in older adults, the appropriate dose to effectively reduce pain in people living with dementia remains unclear (Álvaro González, 2015). The potential side effects of analgesics (e.g., constipation, falls, and

confusion) also need to be considered (Dowell et al., 2016). Families are often unfamiliar with the multitude of considerations involved in decisions, such as whether to administer an opioid medication, causing challenges to clinicians on the medication prescription (De Witt Jansen et al., 2017; Riffin et al., 2022). Clinicians need to focus on the residents' comfort while addressing the family's concerns when conflicts arise regarding the use of medications (Monroe et al., 2015). Finally, partnership with involved family members is essential for pain management and specifically in scenarios where consent to the use of opioid analgesics for those unable to give consent themselves is required (Peisah et al., 2014).

### **Enhancing Staff Education and Communications with Family Carers**

Pain management of people living with dementia in long-term care and acute care settings has several challenges leading to insufficient assessment and treatment of residents' pain. The reduced ability of residents to report pain brings challenges to an appropriate pain assessment and management. In addition, health professionals' lack of awareness of pain and knowledge of using appropriate pain assessment tools constitute some of the significant difficulties in pain management and further prevent family involvement (Giménez-Llort et al., 2020; Zwakhalen et al., 2018). Further challenges arise from the organisational-level high turnover rates among care workers leading to a lack of familiarity and stability in the care worker–resident relationship, particularly in long-term care. This could have an impact on the family–clinician communication regarding pain. Strategies to strengthen family carers and clinician partnerships are needed to ensure pain is identified and better managed to minimise suffering, adverse outcomes, and loss of quality of life from pain in people living with dementia (Fry et al., 2017). Evidence shows that an integrated and standardised protocol for comprehensive pain management in advanced dementia, including nurse training on using observational pain assessment tools, development of individualised pharmacological and nonpharmacological actions and reassessment with record-keeping, leads to better pain

management in people with advanced dementia in an acute geriatric unit (Montoro-Lorite et al., 2020). Moreover, the International Family Nursing Association Position Statement on Generalist Competencies for Family Nursing Practice provides competencies for undergraduate level or generalist level nurses to guide nursing practice to involve families in care process (International Family Nursing Association, 2015). Further research is needed to educate families and healthcare professionals in detecting and assessing pain and enhancing and facilitating partnership engagement and communications.

### **Strengths and Limitations**

Family carers play an important role in caring for people with dementia and need continued support for pain management. This comprehensive review of the literature is the first attempt to summarise evidence for family involvement in pain management of people living with dementia. This review identified that only a few studies have focused on family carers' needs and strategies to support pain management in people living with dementia, representing a research gap in the literature. In addition, there is limited information on healthcare professionals and the working relationship of families and healthcare professionals. Moreover, as only articles written in English were considered, potentially relevant articles written in another language may have been missed. As most of the included studies were qualitative, the review findings are limited to what was reported within their findings, which may bias the review results.

### **Relevance to Clinical Practice**

This study has generated new knowledge that has significant implications for clinical settings, transforming pain management practice and reducing pain in people living with dementia. First, pain management for older people with dementia is best achieved with an integrated approach, including family carers and healthcare professionals. Second, most studies in this review were conducted in nursing homes and communities; limited studies

were conducted in acute care settings. With an increasing number of hospitalised older people with dementia it is imperative to explore how families could be involved in pain management for those hospitalised. Third, with the growing population of people living with dementia, the need for the continued support of family carers also increases. We must acknowledge the expanding surrogacy role family carers play in improving pain management in people living with dementia and develop programs to support their needs.

### **Conclusions**

Pain is a common problem among older adults living with dementia, but it is often undiagnosed and undertreated. Pain management is a key aspect of the family carer role, although many family carers are not actively involved in the pain management of people living with dementia. This review synthesized the current evidence of family involvement in pain management for people living with dementia. Family carers had insufficient support and communication with the care team to address their family members' pain-related needs. In addition, both healthcare providers and families need formal and structured pain identification and management training to support quality pain management in dementia care. Future research should design educational programs for healthcare professionals and family carers to improve their pain management knowledge and skills, communication, and engagement in care. It is also critical to investigate effective interventions to support healthcare cooperation and communication with family carers for pain assessment and management of people with dementia.

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## **Captions for Tables and Figures**

### **Table 1.**

**Summary of the quality assessment of the included studies using the Mixed Methods Appraisal Tool (MMAT)**

### **Table 2.**

**Study characteristics**

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**Results synthesis**

### **Figure 1.**

**PRISMA flow diagram**

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**PRISMA checklist**

### **Supplementary file 2.**

**Search keywords and search history**

## Tables

**Table 1.**

### Summary of the quality assessment of the included studies using the Mixed Methods Appraisal Tool (MMAT)

Types of study design	Methodological quality criteria	Barry 2015	Buffum 2007	Bullock 2020	Corbett 2016	Falls 2004	Lichtner 2016	Lundin 2021	Martin 2005	Mentes 2004	Newton 2018	Riffin 2022	Tarter 2016
Screening	Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?	√	√	√	√	√	√	√	√	√	√	√	√
	Do the collected data allow to address the research question (objective)?	√	√	√	√	√	√	√	√	√	√	√	√
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	-	-	√	-	√	√	√	√	√	√	√	√
	1.2. Are the qualitative data collection methods adequate to address the research question?	-	-	√	-	√	√	√	√	√	√	√	√
	1.3. Are the findings adequately derived from the data?	-	-	√	-	√	√	√	√	√	√	√	√
	1.4. Is the interpretation of results sufficiently substantiated by data?	-	-	√	-	√	√	√	√	√	√	√	√
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	-	-	√	-	√	√	√	√	√	√	√	√
2. Quantitative descriptive studies	2.1. Is the sampling strategy relevant to address the research question?	√	×	-	-	-	-	-	-	-	-	-	-

	2.2. Is the sample representative of the target population?	√	√	-	-	-	-	-	-	-	-	-	-
	2.3. Are measurements appropriate?	?	×	-	-	-	-	-	-	-	-	-	-
	2.4. Is the risk of nonresponse bias low?	×	×	-	-	-	-	-	-	-	-	-	-
	2.5. Is the statistical analysis appropriate to answer the research question?	√	√	-	-	-	-	-	-	-	-	-	-
<b>3. Mixed methods</b>	3.1 Is there an adequate rationale for using a mixed methods design to address the research question?	-	-	-	√	-	-	-	-	-	-	-	-
	3.2 Are the different components of the study effectively integrated to answer the research question?	-	-	-	√	-	-	-	-	-	-	-	-
	3.3 Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	-	-	-	√	-	-	-	-	-	-	-	-
	3.4 Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	-	-	-	√	-	-	-	-	-	-	-	-
	3.5 Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	-	-	-	√	-	-	-	-	-	-	-	-

Note: “√” = yes; “×” = no; “?” = cannot tell; “-” = not applicable

**Table 2.**

**Study characteristics**

<b>ID</b>	<b>Citation Country</b>	<b>Study/Interview Questions</b>	<b>Study design</b>	<b>Setting</b>	<b>Sample size</b>	<b>Conclusions and implications</b>
1	Barry et al., 2015  Ireland	What are the perceptions of relatives of residents with dementia of care provided by the care home and the treatment of pain?	Survey with structured face-to-face interviews	Dementia care homes	Total n = 93  Relatives of residents (n = 35), residents (n = 42), and nurses/care assistants (n = 16)	<ul style="list-style-type: none"> <li>• Relatives of the residents sampled reported that pain was managed appropriately by the care home.</li> <li>• It is challenging for care home providers and clinical staff to conduct the assessment and management of pain in care home residents with dementia.</li> </ul>
2	Buffum et al., 2007  USA	<p>What are family caregivers' perspectives on their communication with professional caregivers about pain management when their family members with dementia enter unfamiliar healthcare settings?</p> <p>What are family caregivers' perspectives about pain management once their family members with dementia have entered these new settings?</p>	A pilot exploratory study with survey	Hospital and nursing home	Total n = 34  Family cares (n = 34) who cared for a family member with dementia	<ul style="list-style-type: none"> <li>• Family caregivers are concerned about pain management when their family members with dementia enter unfamiliar care settings.</li> <li>• Pain information is not communicated between family caregivers and staff in new care settings.</li> <li>• The need for staff members' increased knowledge, attention to patients, and communication with</li> </ul>

						other staff and family.
3	Bullock et al., 2020 UK	To explore pain identification, assessment, and management in community-dwelling people with dementia.	Semi-structured interviews	Community	Total n = 31  Family cares (n = 9), people with dementia (n = 8), general practitioner (n = 9), old-age psychiatrist (n = 5)	<ul style="list-style-type: none"> <li>• Family caregivers were responsible for the day-to-day identification, assessment, monitoring, and subsequent management of pain.</li> <li>• Family caregivers reported the challenge of identifying when a person with dementia might be experiencing pain in the absence of self-report.</li> <li>• Family caregivers described awareness of behavioural, psychological, and physical changes that may be indicative of pain for people with dementia;</li> <li>• Non-drug strategies were identified as safer pain management approaches than the multifactorial concerns associated with analgesic treatment.</li> </ul>

4	Corbett et al., 2016 UK	To explore the current landscape of pain management in people with dementia living in care home settings.	Mixed-methods	Care homes	Total n = 22  Two family groups (n =10) and care staff (n = 12)	<ul style="list-style-type: none"> <li>• Pain is common in people with dementia living in care homes. However, no specific guidance or care programme is provided to address pain management in this setting.</li> <li>• Care home staff appear to lack the confidence, training, and support of family caregivers to participate in pain management proactively.</li> </ul>
5	Falls et al., 2004 Australia	<p>What is the current state of pain management in people with dementia in care homes?</p> <p>What are the barriers and opportunities for improvement?</p>	A grounded theory approach with semi-structured interviews	Aged care facilities	Total n = 31  Informal carers (spouses and relatives, n =15) and formal cares (n = 16)	<ul style="list-style-type: none"> <li>• There was no single set of reliable signs or behaviours that identified pain in individuals with dementia. Carers could detect deviations from normal behaviours because they intimately know the person with dementia developed from close and ongoing contact.</li> <li>• Effective pain assessment for people with dementia is dependent on carers having an intimate knowledge of the individual's normal state of being with dementia.</li> </ul>

6	Lichtner et al., 2016 UK	To investigate how pain is recognised, assessed, and managed in patients with dementia in a range of acute hospital wards to inform the development of a decision support tool to improve pain management.	Semi-structured interviews	Hospital	Total n = 56 Family members ('carers', n = 4) and health care staff (n = 52)	<ul style="list-style-type: none"> <li>• Recognition, assessment and management of pain in patients with dementia in hospital wards should involve information sources from different perspectives.</li> </ul>
7	Lundin et al., 2021 Sweden	To describe nurses' experiences caring for people with advanced dementia and pain at the end of life.	Individual qualitative, semi-structured interviews	Nursing homes	Total n = 13 13 nurses	<ul style="list-style-type: none"> <li>• Relatives can affect the assessment and management of pain due to the reduced ability to communicate.</li> <li>• Good communication and relationships with healthcare staff and relatives could facilitate good pain management.</li> </ul>
8	Martin et al., 2005 Canada	To explore informal caregivers' perspectives of seniors with dementia on the current status of pain assessment and management.	Qualitative study focus groups interviews	Community	Total n = 45 Relatives (n = 8) for people with dementia, older people with dementia (n = 12), and health professionals (n = 25)	<ul style="list-style-type: none"> <li>• Highlighted the need for pain-control strategies beyond medication towards a multidimensional approach to assessing and treating pain for older people.</li> </ul>

9	Mentes et al., 2004  USA	How did your relative express pain before coming to the nursing home?  How did s/he treat pain before coming to the nursing home?	Qualitative semi-structured interviews	Nursing homes	Total n = 27  Family members or friends (n = 16) and certified nursing assistants (n = 11) for residents with cognitive impairment	<ul style="list-style-type: none"> <li>• Scheduling a family interview on admission to the nursing home would provide information about a relative's pain expression and personal history.</li> <li>• Family interviews at admission could be invaluable in helping staff with pain detection and can direct a pain management plan for cognitively impaired residents.</li> <li>• Family members have important information about residents' pain experiences. Nursing home nurses should incorporate this into initial care plans family members' essential information about a resident's prior and current pain expression.</li> </ul>
10	Newton et al., 2018  UK	To explore informal carers' experiences of identifying and managing oral pain and discomfort in people living with dementia and barriers and enablers they encountered.	A qualitative exploratory study with focus groups	Community	Total n = 35  Informal carers (n = 35) of people living with dementia	<ul style="list-style-type: none"> <li>• Carers need more partnership work with dental professionals, and clearer care pathways are required to meet the oral health needs of people living with dementia who experience oral pain.</li> </ul>

11	Riffin et al., 2022 USA	To explore how ambulatory care providers and family caregivers of persons with dementia view pain communication.	In-depth, semi-structured interviews	Medical practices via clinician referral and from community settings	Total n = 34 Family caregivers (n = 18) and healthcare providers involved in dementia care (n = 16).	<ul style="list-style-type: none"> <li>• Receipt of inadequate information and interpersonal conflict are key challenges to caregiver-provider communication regarding pain in persons with dementia.</li> <li>• Written records, pain scales and rapport-building strategies may help to address challenges.</li> </ul>
12	Tarter et al., 2016 USA	To gain insight into the informal caregiving experience of pain management for patients with dementia in hospice.	Qualitative study interviews with informal caregivers of hospice patients with dementia who had chosen pain as the challenge	Hospice agencies	Total n = 51 Informal caregivers (n = 51) caring for patients receiving home hospice services.	<ul style="list-style-type: none"> <li>• The need for increased support for caregivers, including educational interventions targeting pain etiology and assessment and improved communication with healthcare professionals.</li> </ul>

**Table 3.**

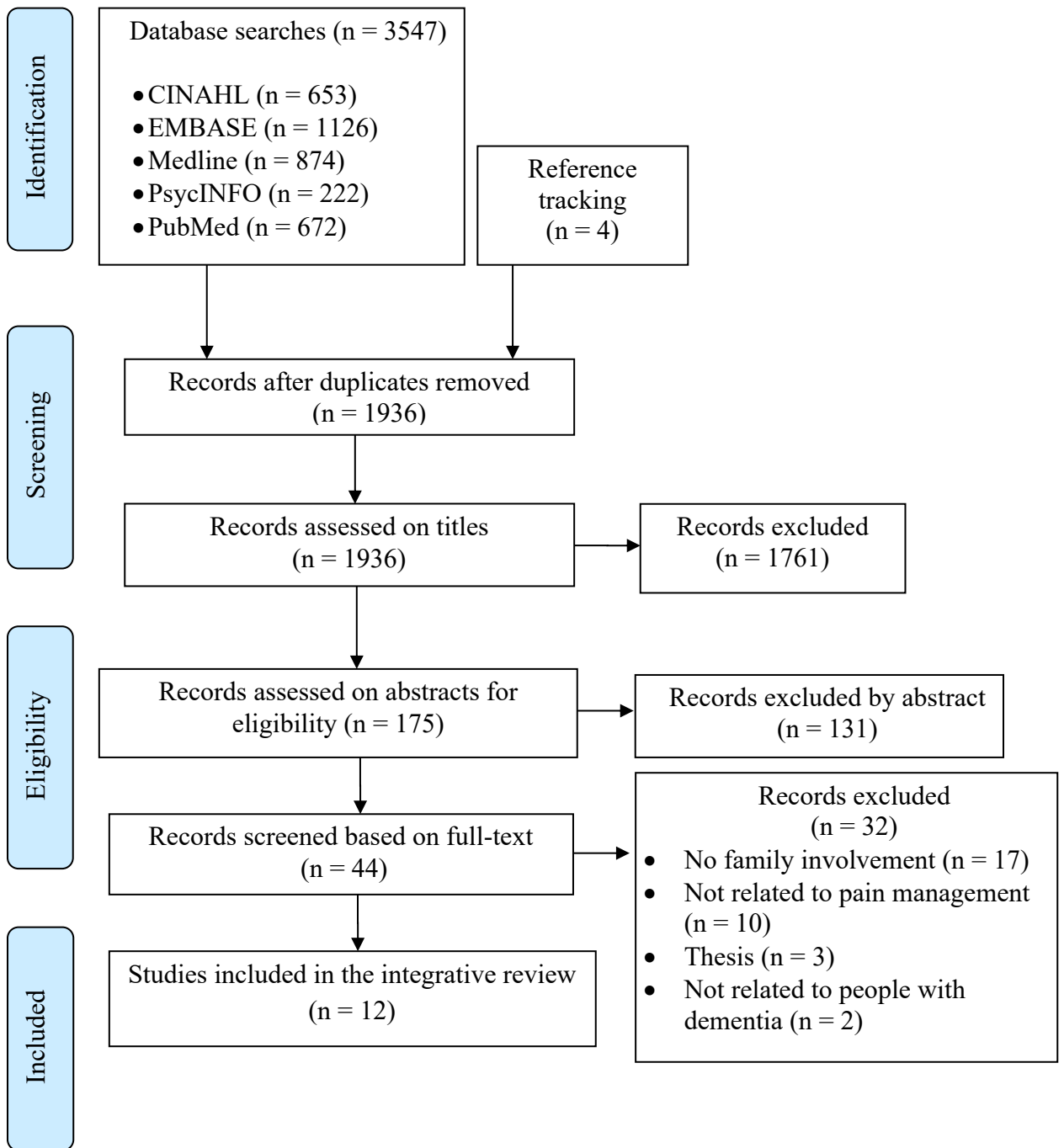
**Results synthesis**

<b>Themes</b>	<b>Subthemes</b>	<b>Examples</b>
<b>1. The roles and responsibilities of families</b>	1.1 Families' roles and responsibilities in pain management for people living with dementia	<ul style="list-style-type: none"> <li>• Families are responsible for initiating non-drug treatments and analgesic use for people with dementia, monitoring and providing feedback information (Bullock et al., 2020)</li> <li>• Family members were identified as key players within the pain management communication network that requires close working between family and care staff (Corbett et al., 2016; Lundin &amp; Godskesen, 2021)</li> <li>• Family caregivers were responsible for the day-to-day identification, assessment, monitoring, and subsequent management of pain (Lichtner et al., 2016)</li> <li>• Caregiver roles - family caregivers, assumed in pain-related consultations: historians, interpreters, and advocates for their care recipient (Tarter et al., 2016)</li> </ul>
	1.2 Challenges of undertaking family roles	<ul style="list-style-type: none"> <li>• Disparities in staff responsibility and confidence: "Not being heard; close working between family and care staff, an active role in pain management" (Corbett et al., 2016)</li> <li>• Interdisciplinary team approach (Martin et al., 2005)</li> </ul>
<b>2. Enablers and barriers for pain identification</b>	2.1 Cognitive and communicative impairments as significant barriers	<ul style="list-style-type: none"> <li>• Cognitive and communicative impairments as significant barriers (Corbett et al., 2016)</li> <li>• Issues related to language and cognitive impairment (Lichtner et al., 2016)</li> <li>• Communication problems-nonverbal clues, difficulty in communicating with patients (Martin et al., 2005; Menten et al., 2004; Tarter et al., 2016)</li> </ul>
	2.2 Be familiar with the person	<ul style="list-style-type: none"> <li>• Knowing the person and the importance of person-centredness and individualisation of pain management (Corbett et al., 2016)</li> <li>• Changes before and after dementia (Falls &amp; Stevens, 2004)</li> <li>• Infrequently used casual and agency staff are not the best choice for working in dementia units (Falls &amp; Stevens, 2004)</li> <li>• Issues of trust and familiarity (Lichtner et al., 2016)</li> <li>• Increased familiarity with the person doing the assessment (Martin et al., 2005)</li> <li>• Lack of/inconsistency of staff (Martin et al., 2005)</li> <li>• Importance of family input about previous pain behaviours in knowing the resident (Menten</li> </ul>

		<p>et al., 2004)</p> <ul style="list-style-type: none"> <li>• More than one third (37.5%) of relatives stated they thought their family member had pain “most” or “all” of the time (Mentes et al., 2004)</li> <li>• Have nurses who speak the same language (Mentes et al., 2004)</li> </ul>
	2.3 Signs and symptoms to identify pain	<ul style="list-style-type: none"> <li>• A person-centred approach for identifying unique individual pain behaviours and for detecting and interpreting pain-related changes in a resident (Corbett et al., 2016)</li> <li>• Assessing the presence of pain: behaviour, facial expression, verbal expression (Falls &amp; Stevens, 2004)</li> <li>• With patients with more severe dementia, the patient’s body language and other cues were studied to infer pain intensity (Lichtner et al., 2016)</li> <li>• Putting a picture together- combine audit data and observations (Lichtner et al., 2016)</li> <li>• Observation of behaviours that signal the presence of pain (e.g., grimacing, frowning of the brow, guarding, rubbing the affected area, physical withdrawal from touch) and changes in mood (e.g., irritability, impatience, frustration, depression) or behaviour (e.g., sleep patterns, eating patterns) (Martin et al., 2005)</li> <li>• Rubbing the affected area, specifically legs and hands; displaying increased irritability or agitation; moaning or gurgling; and making facial grimaces, specifically pursed lips and squinty eyes (Mentes et al., 2004)</li> <li>• Spotting signs and symptoms: pointing/holding face/facial expression; trouble sleeping/relaxing; ‘Bad breath’; ‘Drooling’: Anger; ‘Body language’: (jumpy)/non-verbal/crying (Newton et al., 2018)</li> </ul>
	2.4 Regular observation and assessment of pain	<ul style="list-style-type: none"> <li>• One-fifth of relatives felt that the resident experienced pain that went unnoticed or untreated by the care home (Barry et al., 2015)</li> <li>• More than one third (37.5%) of relatives stated they thought their family member had pain “most” or “all” of the time (Mentes et al., 2004)</li> <li>• Regular observation and assessment (Buffum &amp; Haberfelde, 2007)</li> <li>• Information regarding the temporality of pain and changes in pain experience (rather than a score at a single point in time) seemed to be most beneficial to the assessment of pain (Lichtner et al., 2016)</li> </ul>

		<ul style="list-style-type: none"> <li>• Be constantly vigilant in respect to their patients; communication, spend time and talk to the resident (Mentes et al., 2004)</li> <li>• Need for day-to-day contact: able to establish a deviation from the individual's 'norm' (Newton et al., 2018)</li> </ul>
<b>3. Strategies and concerns for pain management</b>	3.1 Medication administration and concerns related to medications	<ul style="list-style-type: none"> <li>• Maintenance doses of safe medications and evaluation for physical pain should be done (Buffum &amp; Haberfelde, 2007)</li> <li>• Trials with therapy and reassessment (Lichtner et al., 2016)</li> <li>• Reliance on pharmacological treatments and increased concerns of side effects, interactions, and polypharmacy (Bullock et al., 2020)</li> <li>• Treatment challenges and concerns: lack of treatment/under medication, medication side effects, fear of addiction to opioids, lack of alternatives to medications (Martin et al., 2005)</li> <li>• Family members can present challenges to clinicians, especially when clinicians involve them in the pain management decision-making process, such as the use of opioid analgesia, as they are fear of the medication side effects (Riffin et al., 2022)</li> </ul>
	3.2 Non-pharmacological methods	<ul style="list-style-type: none"> <li>• Psychosocial support, spiritual support (e.g., touch, massage) (Buffum &amp; Haberfelde, 2007)</li> <li>• Non-drug strategies provide warmth and comfortable (wheat bags, hot water bottles), massage and distraction techniques (Bullock et al., 2020)</li> <li>• Re-positioning (Lichtner et al., 2016)</li> <li>• Rest, relaxation, music and massage, social and recreational activities, exercise, distraction (Martin et al., 2005)</li> <li>• Lying down in a quiet room, relaxation, physical therapy, and exercise. "face is more relaxed, moves better, more talkative and would sleep better." (Mentes et al., 2004)</li> </ul>

<b>4. Lack of staff education and communications with healthcare providers.</b>	4.1 Lack of staff education/training	<ul style="list-style-type: none"> <li>• Lack of pain awareness in staff (Buffum &amp; Haberfelde, 2007; Corbett et al., 2016)</li> <li>• Current lack of staff training in pain and the importance of understanding the range of intensities and types of pain, and the need for staff to consider sources of pain as a first-line response to changes in behaviour or symptoms (Corbett et al., 2016)</li> <li>• Staff were not perceived as experts in the knowledge of the person they care about (Lichtner et al., 2016)</li> <li>• Improve education of healthcare providers (Lundin &amp; Godskesen, 2021; Martin et al., 2005)</li> <li>• Ambiguity about pain and dementia and pre-existing beliefs and emotions of caregivers (Riffin et al., 2022)</li> <li>• Uncertainty about the etiology of pain (Tarter et al., 2016)</li> </ul>
	4.2 Challenges and recommendations for communication and information exchange with care providers	<ul style="list-style-type: none"> <li>• Relatives are not kept well informed about the resident’s medical condition (Barry et al., 2015)</li> <li>• Communication is a core element for pain management (Corbett et al., 2016)</li> <li>• Carer-clinician communication: Several carers perceived staff to be occupied and therefore were reluctant to initiate a conversation (Lichtner et al., 2016)</li> <li>• Families received inadequate information and patient–family disagreements about the individual’s pain (Riffin et al., 2022)</li> <li>• A lack of proactive communication primarily related to pain (Tarter et al., 2016)</li> <li>• A good way for a family advocate to see if they’re (staff) catching things that are a problem for the patient who has a problem verbalising (Buffum &amp; Haberfelde, 2007)</li> <li>• Educational interventions for family caregivers to more effectively communicate with providers and support pain management (Corbett et al., 2016; Lundin &amp; Godskesen, 2021)</li> <li>• Need for clinicians to improve communication skills with carers (Lichtner et al., 2016)</li> <li>• Increased documentation and staff communication (Martin et al., 2005; Newton et al., 2018)</li> <li>• Approaches and recommendations to improve communication, including the use of written records, pain scales and follow-up discussions, and collaboration and rapport-building strategies (Riffin et al., 2022)</li> </ul>



**Figure 1. PRISMA flow diagram**

## Supplementary file 2 Search history

Table 1 Medical subject headings (MeSH) and keywords used in searches

CINAHL subject heading	MeSH terms	Keywords
(MH "Dementia") OR (MH "Frontotemporal Dementia+") OR (MH "Dementia, Vascular+") OR (MM "Lewy Body Disease") OR (MM "Dementia Patients")	Dementia OR "Alzheimer Disease"	Dementia OR Alzheimer* OR "cognitive impairment" OR "cognitive decline" OR "cognition disorders"
(MH "Family+") OR (MH "Family Attitudes+") OR (MM "Caregivers") OR (MH "Caregiver Attitudes") OR (MM "Caregiver Burden") OR (MM "Caregiver Support") OR (MM "Spouses") OR (MM "Adult Children")	"Caregivers" OR "Family" OR "Spouses" or "Adult Children"	caregiv* OR carer* OR famil* OR "informal carer*" OR "support person" OR caretaker* OR spouse* OR husband* or wife or wives OR partner* OR "loved one*" OR mother* OR father* OR "adult child*" OR son* OR daughter* OR "next of kin" OR friend* OR relative*
(MH "Pain+") OR (MM "Pain Measurement") OR (MM "Pain Management") OR (MH "Analgesia+")	"Pain" OR "Pain Measurement" OR "Pain Management" OR "Analgesia"	pain* OR "pain manag*" OR "pain measur*" OR "pain parameter*" OR "pain evaluat*" OR "pain assess*" OR "pain tool*" OR "pain experience*" OR "pain score*" OR "pain scale*" OR "pain diagnos*" OR "pain screen*" OR analges*

**CINAHL (EBSCO)**

#	Query	Limiters/Expanders	Last Run Via	Results
S15	S3 AND S9 AND S13	Expanders - Apply equivalent subjects Narrow by Language: - English Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	653
S14	S3 AND S9 AND S13	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	678
S13	S10 OR S11 OR S12	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	339,528
S12	AB pain* OR "pain manag*" OR "pain measur*" OR "pain parameter*" OR "pain evaluat*" OR "pain assess*" OR "pain tool*" OR "pain experience*" OR "pain score*" OR "pain scale*" OR "pain diagnos*" OR "pain screen*" OR analges*	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	221,813
S11	(MH "Analgesia+")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases	15,262

			Search Screen - Advanced Search Database - CINAHL Complete	
S10	(MH "Pain+") OR (MM "Pain Measurement") OR (MM "Pain Management")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	214,762
S9	S4 OR S5 OR S6 OR S7 OR S8	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	768,307
S8	(MM "Adult Children")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	1,676
S7	(MM "Spouses")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	6,690
S6	(MH "Family+") OR (MH "Family	Expanders - Apply equivalent subjects	Interface - EBSCOhost	251,479

	Attitudes+")	Search modes - Boolean/Phrase	Research Databases Search Screen - Advanced Search Database - CINAHL Complete	
S5	AB caregiv* OR carer* OR famil* OR "informal carer*" OR "support person" OR "caretaker*" OR spous* OR husband* or wife or wives OR partner* OR "loved one*" OR mother* OR father* OR "adult child*" OR son* OR daughter* OR "next of kin" OR friend* OR relative*	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	625,123
S4	(MM "Caregivers") OR (MH "Caregiver Attitudes") OR (MM "Caregiver Burden") OR (MM "Caregiver Support")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	29,338
S3	S1 OR S2	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	104,493
S2	AB Dementia OR Alzheimer* OR "cognitive impairment" OR "cognitive decline" OR "cognition disorders"	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL	67,887

			Complete	
S1	(MH "Dementia+") OR (MH "Frontotemporal Dementia+") OR (MH "Dementia, Vascular+") OR (MM "Lewy Body Disease") OR (MM "Dementia Patients")	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	Interface - EBSCOhost Research Databases Search Screen - Advanced Search Database - CINAHL Complete	75,588

### MEDLINE (OVID)

#	Searches	Advanced	Type
4	1 and 2 and 3	874	Advanced
3	(Pain or Pain Measurement or Pain Management or Analgesia).sh. or (pain* or pain manag* or pain measur* or pain parameter* or pain evaluat* or pain assess* or pain tool* or pain experience* or pain score* or pain scale* or pain diagnos* or pain screen* or analges*).ab.	656801	Advanced
2	(Caregivers or Family or Spouses or Adult Children).sh. or (caregiv* or carer* or famil* or informal carer* or support person or caretaker* or spous* or husband* or wife or wives or partner* or loved one* or mother* or father* or adult child* or son* or daughter* or next of kin or friend* or relative*).ab.	2485205	Advanced
1	(Dementia or Alzheimer Disease).sh. or (Dementia or Alzheimer* or cognitive impairment or cognitive decline or cognition disorders).ab.	233315	Advanced

EMBASE	
No.Query	Results
#18	1,126
#16 AND ([adult]/lim OR [aged]/lim OR [middle aged]/lim OR [very elderly]/lim) AND ('article'/it OR 'article in press'/it OR 'review'/it)	
#17	1,753
#16 AND ([adult]/lim OR [aged]/lim OR [middle aged]/lim OR [very elderly]/lim)	
#16	3,363
#3 AND #9 AND #14 AND [English]/lim	
#15	3,561
#3 AND #9 AND #14	
#14	1,829,184
#10 OR #11 OR #12 OR #13	
#13	1,145,470
pain*:ti,ab,kw OR 'pain manag*':ti,ab,kw OR 'pain measur*':ti,ab,kw OR 'pain parameter*':ti,ab,kw OR 'pain evaluat*':ti,ab,kw OR 'pain assess*':ti,ab,kw OR 'pain tool*':ti,ab,kw OR 'pain experience*':ti,ab,kw OR 'pain score*':ti,ab,kw OR 'pain scale*':ti,ab,kw OR 'pain diagnos*':ti,ab,kw OR 'pain screen*':ti,ab,kw OR analges*:ti,ab,kw	
#12	174,587
'analgesia'/exp	
#11	18,075
'pain measurement'/exp	
#10	1,380,583
'pain'/exp	
#9	4,104,885
#4 OR #5 OR #6 OR #7 OR #8	
#8	3,898,631
caregiv*:ti,ab,kw OR carer*:ti,ab,kw OR famil*:ti,ab,kw OR 'informal carer*':ti,ab,kw OR 'support person':ti,ab,kw OR 'caretaker*':ti,ab,kw OR spous*:ti,ab,kw OR husband*:ti,ab,kw OR wife:ti,ab,kw OR wives:ti,ab,kw OR partner*:ti,ab,kw OR 'loved one*':ti,ab,kw OR mother*:ti,ab,kw OR father*:ti,ab,kw OR 'adult child*':ti,ab,kw OR son*:ti,ab,kw OR daughter*:ti,ab,kw OR 'next of kin':ti,ab,kw	

OR friend*:ti,ab,kw OR relative*:ti,ab,kw	
#7	1,540
'adult child'/exp	
#6	19,931
'spouse'/exp	
#5	529,165
'family'/exp	
#4	84,442
'caregiver'/exp	
#3	411,074
#1 OR #2	
#2	381,571
dementia:ti,ab,kw OR alzheimer*:ti,ab,kw OR 'cognitive impairment':ti,ab,kw OR 'cognitive decline':ti,ab,kw OR 'cognition disorders':ti,ab,kw	
#1	205,423
'alzheimer disease'/exp	
PsycINFO (OVID)	
1	(Dementia or Alzheimer Disease).mh. or (Dementia or Alzheimer* or cognitive impairment or cognitive decline or cognition disorders).ab. 119458
2	(Caregivers or Family or Spouses or Adult Children).mh. or (caregiv* or carer* or famil* or informal carer* or support person or caretaker* or spous* or husband* or wife or wives or partner* or loved one* or mother* or father* or adult child* or son* or daughter* or next of kin or friend* or relative*).ab. 947054
3	(Pain or Pain Measurement or Pain Management or Analgesia).mh. or (pain* or pain manag* or pain measur* or pain parameter* or pain evaluat* or pain assess* or pain tool* or pain experience* or pain score* or pain scale* or pain diagnos* or pain screen* or analges*).ab. 117464
4	1 and 2 and 3 569
5	limit 4 to ("380 aged <age 65 yrs and older>" and english) 222

PubMed

Search: (((Dementia or Alzheimer Disease[MeSH Terms]) OR (Dementia[Title/Abstract] OR Alzheimer\*[Title/Abstract] OR cognitive impairment[Title/Abstract] OR cognitive decline[Title/Abstract] OR cognition disorders[Title/Abstract])) AND ((Caregivers or Family or Spouses or Adult Children[MeSH Terms]) OR (caregiv\*[Title/Abstract] OR carer\*[Title/Abstract] OR famil\*[Title/Abstract] OR informal carer\*[Title/Abstract] OR support person[Title/Abstract] OR caretaker\*[Title/Abstract] OR spous\*[Title/Abstract] OR husband\*[Title/Abstract] OR wife[Title/Abstract] OR wives[Title/Abstract] OR partner\*[Title/Abstract] OR loved one\*[Title/Abstract] OR mother\*[Title/Abstract] OR father\*[Title/Abstract] OR adult child\*[Title/Abstract] OR son\*[Title/Abstract] OR daughter\*[Title/Abstract] OR next of kin[Title/Abstract] OR friend\*[Title/Abstract] OR relative\*[Title/Abstract]))) AND ((Pain or Pain Measurement or Pain Management or Analgesia[MeSH Terms]) OR (pain\*[Title/Abstract] OR pain manag\*[Title/Abstract] OR pain measur\*[Title/Abstract] OR pain parameter\*[Title/Abstract] OR pain evaluat\*[Title/Abstract] OR pain assess\*[Title/Abstract] OR pain tool\*[Title/Abstract] OR pain experience\*[Title/Abstract] OR pain score\*[Title/Abstract] OR pain scale\*[Title/Abstract] OR pain diagnos\*[Title/Abstract] OR pain screen\*[Title/Abstract] OR analges\*[Title/Abstract])) Filters: English, Adult: 19-44 years, Aged: 65+ years