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Pain Assessment and Management in Dementia Care: Qualitative Perspectives of People With Dementia, Their Families, and Healthcare Professionals

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ABSTRACT

Aim: Pain is under-assessed and under-treated among people living with dementia. This study aims to explore the perspectives of people with dementia, family carers, and healthcare professionals regarding their experiences and needs for pain assessment and management.

Design: A qualitative descriptive approach.

Methods: Between May and August 2023, people with early-stage dementia ($n=6$), their family carers ($n=7$), and healthcare professionals ($n=10$) from four Australian states participated in semi-structured interviews, online or by telephone. Most of the participants were female. Work experience of healthcare professionals and caring experience of carers ranged from 3–40 and 2–8 years, respectively. Following transcription, the data were analysed using inductive thematic analysis.

Results: Four main themes and 10 subthemes were identified. Main themes were (1) communications to identify pain in people with dementia, (2) pain assessment in people with dementia, (3) pain management strategies, and (4) training in pain and dementia care. Healthcare professionals and family carers reported challenges in pain identification. People with dementia also mentioned their pain being unrecognised by carers. Facilitators included familiarity and communication with people with dementia and family carers. Non-verbal cues and unusual behaviours were commonly used to identify pain, and a personalised pain assessment approach was highlighted. Non-pharmacological strategies were used as the first-line therapy to manage pain. However, a lack of knowledge and training in pain and dementia care indicated the need for a training program (e.g., a self-paced online short course).

Conclusions: Pain assessment and management in people with dementia is challenging, primarily due to communication barriers and a lack of skill training. Formal pain assessment and management training and efficient, easy-to-use pain assessment tools are needed to address this.

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Implications for the Profession and/or Patient Care: Limited communication capacity in people with dementia and lack of training in carers are key challenges regarding pain assessment and management in people with dementia. Improved training in communication, pain assessment, and management skills may help to address these challenges.

Impact: This study addressed a lack of knowledge and skills for healthcare professionals and family carers in effective pain assessment and management in people with dementia. Collaborative communication among different stakeholders and skills training may overcome the challenges and barriers.

Reporting Method: COREQ guidelines were followed when reporting this study.

Patient or Public Contribution: Healthcare professionals, people with dementia, and family carers contributed to the design of interview questions and data collection.

1 | Introduction

Pain is a frequently reported symptom in older adults (defined as those aged 60 or 65 years and older) (United Nations 2024). Up to 80% of older people are affected by pain, and around 50% of people with dementia experience pain regularly (Atee et al. 2021; van Kooten et al. 2017). Despite the high prevalence of pain, there is substantial evidence that most healthcare professionals (i.e., over 90% of registered nurses, general practitioners, and psychiatrists) struggle to assess pain in people with dementia accurately (Bullock et al. 2020; Jennings et al. 2018). Impairments in memory and language impact the ability of people with dementia to communicate their pain to healthcare professionals. Moreover, challenging behaviours such as resisting care, agitation, confusion, and aggression may be manifestations of underlying pain (Graham et al. 2022). In practice, the role of pain in such behaviours is often not considered, which can lead to inappropriate prescriptions of psychotropics rather than pain medications and an increased risk of death (Scuteri et al. 2021). As a result, people with dementia are at higher risk of under-recognised pain and will face substantially greater obstacles in receiving effective pain relief than people without dementia (La Frenais et al. 2021). This can have a negative impact on their quality of life, contributing to delirium (Feast et al. 2018), reduced activities of daily living (van Dalen-Kok et al. 2021), and healthcare costs, which are 25% higher for people without pain (with pain: AUD 8945 vs. without pain: AUD 7161 per resident annually) (Guliani et al. 2021).

Family carers are key in delivering care and support services for people with dementia. However, carers are at high risk for caregiver burden, chronic stress, depression, anxiety, and grief (Steenfeldt et al. 2021). Pain management is one of the carers' most expressed concerns and causes of caregiver burden (Steenfeldt et al. 2021). Due to progressive cognitive and communication decline, effective communication about pain can be extremely challenging for people living with advanced dementia (Rababa 2018). Family carers encounter challenges such as pain identification and communication and using appropriate pain medications (Chi et al. 2022). With an expected increase in the number of people living with dementia and the subsequent demand on family carers, it is imperative to address the needs of carers in assessing and managing pain. Therefore, it is vital to understand the experiences and needs of pain assessment and management in people with dementia from the perspectives of key stakeholders, including people with dementia, their families, and healthcare professionals. Such information can directly

influence clinical practice, contributing to improved pain management and enhanced quality of life for individuals living with dementia.

2 | Background

More than 200,000 Australians live in residential aged care facilities (RACFs), and more than two-thirds (68.1%) of these aged care residents have moderate to severe cognitive impairment (Dementia Australia 2022). This population often receives fewer pain medications than those without dementia (Achterberg et al. 2020). Pain is a critical topic in people with dementia, as there is an identified knowledge-to-practice gap (Anderson et al. 2021). Although clinical guidelines for assessing pain in people with dementia are available, such guidelines are not widely implemented in Australian aged care settings mainly due to resource constraints and gaps in continuing education in pain care (Tsai et al. 2022). Other key barriers in clinical practice include the residents' cognitive impairment, healthcare professionals' lack of knowledge, and the breakdown of communication among multidisciplinary healthcare teams (Knopp-Sihota et al. 2019). Moreover, the difficulties are exacerbated by low staffing and varied skill mix, high staff turnover, insufficient patient contact time, minimal funding for staff resources, and inadequate staff training in the aged care sector. Due to this, pain assessment and management policies often fail to consider the specific needs of people with dementia and their families (Corbett et al. 2016).

Healthcare professionals' knowledge, attitudes, and training gaps contribute to the challenges. First, although pain in dementia can be assessed by systematically observing specific indicators, such as facial expressions, verbalisations/vocalisations, body movements, interpersonal interactions, activity patterns/routines, and mental status (American Geriatric Society 2002), inadequate specialised knowledge and training are major obstacles for healthcare professionals (Gerber et al. 2022; Giménez-Llort et al. 2020). Second, misconceptions about pain and aging are prevalent; for example, pain is a normal part of aging, people with dementia are less sensitive to pain, and lack of pain reporting indicates an absence of pain (Achterberg et al. 2013). Third, despite the importance of quality pain care in clinical practice, pain assessment receives little emphasis in healthcare professional training programs for dementia care (Giménez-Llort et al. 2020). Moreover, people living with dementia and their families are rarely involved in co-designing these training programs (Rapaport et al. 2018).

Summary

- What does this paper contribute to the wider global community?
 - Effective pain management in people with dementia requires collaborative communication among key stakeholders, including people with dementia, their family carers, and healthcare professionals.
 - A multidisciplinary decision-making approach is needed for pain assessment and management.
 - Training programmes need to prioritise effective communication skills and pain assessment skills to reduce the silent suffering of pain in people with dementia.

Therefore, understanding the experiences, expectations, and needs of people living with dementia, their families, and healthcare professionals regarding pain management will address a critical health issue—under-recognised and under-treated pain in people with dementia. This will provide recommendations for training programmes to enhance this population's knowledge, attitudes, and practice in pain assessment and management.

3 | Methods

3.1 | Aim

This study aims to explore the perspectives of people with dementia, their families, and healthcare professionals regarding their experiences and needs for pain assessment and management.

3.2 | Design

A descriptive qualitative study exploring experiences and needs regarding pain assessment and management of people with dementia was conducted with multidisciplinary healthcare professionals, people with dementia, and their families. The study is reported according to the consolidated criteria for reporting qualitative research (COREQ) (Tong et al. 2007) (Appendix S1).

3.3 | Participant Recruitment

We aimed to recruit a purposive sample of people with early-stage dementia, their families, and healthcare professionals. The sampling process was continued until no new codes were found. Hennink and Kaiser (2022) reported that saturation can be achieved in studies involving a relatively homogenous study population and narrow objectives, typically through a narrow range of interviews ranging from 9–17.

Participants were recruited online via Dementia Australia and StepUp for dementia research platforms (Jeon et al. 2021). We obtained a list of eligible participants who fulfilled the study

inclusion and exclusion criteria through these platforms. They were contacted via email and/or a telephone call to identify their interest in participating. Furthermore, those interested in participating were encouraged to contact the researchers directly to receive additional study information via telephone, email, or postal mail.

3.4 | Inclusion Criteria

The inclusion criteria for the three groups are as follows:

- a. Healthcare professionals who are providing care to people with dementia and can communicate in English.
- b. Family members who are providing care or have provided care within the past six months to people with dementia, aged 18 years or older, and who can communicate in English.
- c. People who are living with early-stage dementia in Australia can provide informed consent and can communicate in English. Early-stage dementia involves cognitive impairment and poor performance on cognitive assessments that show a decline from previous abilities. People with mild dementia can still manage simpler daily tasks on their own, unlike those with more severe dementia (Knopman and Petersen 2014).

3.5 | Data Collection

The research team conducted online semi-structured interviews between May and August 2023. Previous research emphasised the importance of allowing participants to choose their interview format to share their experiences and promote inclusion (Lindsay 2022). Additionally, telephone and Zoom interviews with a camera on resulted in a similar word count and number of themes (Lindsay 2022). Therefore, we decided to allow participants to choose to have their interviews conducted via Microsoft Teams or telephone based on their choice. The interviews with healthcare professionals, people living with dementia, and carers were conducted by two female researchers (M.K. Gamage, PhD student in nursing and M. Okada, Master student in psychology) with experience in researching pain and people living with dementia. The interviewers had no relationship with the participants before the commencement of the study. Participants were informed about the researchers' details and the purpose of conducting the research, which was to establish a trusting relationship before beginning the interviews.

Interview questions (Appendix S2) were formulated from previous research evidence (Lichtner et al. 2016; Lundin and Godskesen 2021; Pu et al. 2023) and group discussions with the research team. One registered nurse in dementia care, a person with dementia, and a family carer were consulted, and valuable insights were offered to ensure that the questions were clear and relevant. No repeat interviews were conducted. The interviews were recorded after obtaining consent from the participants.

3.6 | Data Analysis

The interviews were recorded and transcribed verbatim via Microsoft Teams (online interviews) or transcribed manually (telephone interviews). The research team double-checked the transcriptions. After verifying the accuracy of the transcripts, the audio recordings were deleted. Initial coding was inductive and was conducted independently by one researcher (L. Pu) and a research assistant (M.K. Gamage), using NVivo 12 to organise and manage the data. The research team discussed the codes before they were applied to the remaining transcripts. The research team independently reviewed each transcript to identify themes. Then, several discussions were conducted within the research team to finalise the themes. Braun and Clarke's (Clarke et al. 2015) six-step inductive thematic analysis guided the analysis. Transcripts were not returned to participants for their feedback on the findings.

3.7 | Ethical considerations

This study was approved by Griffith University Human Ethics Committee (reference number 2023/169). Participants reviewed the participant information sheet prior to giving their consent to be involved and were explained the study purpose before the interview. All participating people with early-stage dementia, family carers, and healthcare professionals signed written informed consent before joining the interview. Participants with early-stage dementia had the capacity to understand the study and their contribution. The researcher ensured this while explaining the study. Additionally, they were able to provide informed consent.

3.8 | Study Rigour

Strategies aimed at ensuring the trustworthiness of the data, from data collection to analysis, were employed. Despite the research team's collective expertise in qualitative research and interviews, two researchers involved in the data collection and analysis (M.K. Gamage & M. Okada, females) were trained by experienced nursing researchers (W. Moyle & L. Pu, PhD) to communicate and conduct online/telephone interviews, particularly with people with dementia. A study protocol and interview questions minimised researcher disparities during data collection and ensured dependability. A purposive sample was recruited to ensure data transferability; interviews were conducted until the point of saturation to ensure data transferability, and interviews were conducted until saturation was reached to ensure credibility. Additionally, two researchers (L. Pu & M.K. Gamage) independently analysed the data using an audit trail for coding and categorising data to improve the findings' credibility (Nowell et al. 2017). This was strengthened by having team members crosscheck the codes, subthemes, and themes by representing quotations from participants, when possible, to ensure that the participants' views were correctly presented and interpreted. Member cross-checks were conducted during the development of codes, subthemes, and themes. All research team members met regularly during the data collection and analysis periods to ensure the rigour of the process (Cassell and Symon 2011).

The research team used direct quotations to minimise interpreter bias.

4 | Findings

A total of 23 interviews were conducted with participants from four Australian states, namely Queensland, New South Wales, Victoria, and Western Australia. Most of the participants were females. Six healthcare professionals joined individual online interviews and four by telephone. The individual interviews with healthcare professionals ran for a mean (SD, standard deviation) duration of 61.55 (± 18.17) minutes with a median duration of 65.94 min. Their current roles included general practitioner ($n = 1$), speech pathologist ($n = 2$), dementia support nursing specialist ($n = 2$), nurse educator ($n = 1$), nurse consultant ($n = 1$), and registered nurse ($n = 3$). They worked in acute care hospitals and residential aged care facilities. Their ages ranged from 32 to 70 years, and work experience ranged from three to 40 years. Nine had dementia training, but only four had training in pain management for people living with dementia. We conducted seven individual interviews with family carers. The interviews ran for a mean (SD) duration of 34.00 (± 7.15) minutes with a median duration of 36.68 min. Most carers were female ($n = 6$) and the daughters of the care recipients ($n = 5$). One carer was a wife ($n = 1$), and the other carer was a husband ($n = 1$). Some participants were living with a family member with dementia ($n = 3$). Two participants had recent experience caring for their family members living with dementia. In one case, a family member shared the caregiving with another family member. Their ages ranged from 37 to 75 years, and caring experience ranged from 2 to 8 years. The individual interviews with people living with dementia ran for a mean (SD) duration of 26.50 (± 16.6) minutes with a median duration of 22.10 min. Most were females ($n = 4$), and their ages ranged from 67 to 81 years (Table 1).

Four main themes and 10 subthemes were identified from the data analysis. The themes included (1) communications to identify pain in people with dementia, (2) pain assessment in people with dementia, (3) pain management strategies, and (4) training in pain and dementia care. The themes and subthemes are presented (Table 2) with exemplar quotations and participant information.

Healthcare professionals and family carers reported challenges in pain identification. People with dementia also mentioned their pain being unrecognised by their carers. Facilitators to mitigate these challenges included familiarity and direct communication with people with dementia and family carers. Moreover, non-verbal cues and unusual behaviours were commonly used to identify pain in people with dementia, while limitations of using pain assessment tools included the ambiguity and challenges of involving people with dementia in the assessment process. Therefore, healthcare professionals, family carers, and people with dementia highlighted the need for a personalised pain assessment approach with a more user-friendly tool that could combine personal assessment and information from both the people with dementia themselves and their carers. In addition, non-pharmacological strategies were used as the first-line therapy to manage pain due to the concerns of polypharmacy and side effects of pain medications. However, a lack of knowledge and training in

TABLE 1 | Characteristics of participants.

Group 1	Work					Training in dementia care	Training in pain management
	ID	Current roles	Sex	Age, years	Work experience, years	Highest level of education	
Healthcare professionals	1	General practitioner	Female	62	32	Postgraduate	No
	2	Speech pathologist	Female	35	13	Masters	No
	3	Clinical nurse consultant	Female	55	10	Graduate Diploma	Online modules
	4	Dementia support specialist	Female	46	3	Bachelor	Currently undertaking a Bachelor's in dementia care
	5	Dementia support specialist	Male	69	50	Bachelor	No
	6	Registered nurse	Female	34	15	Bachelor	A course of dementia support Australia
	7	Registered nurse	Female	63	30	Postgraduate	Certificate in Geriatric care
	8	Clinical nurse educator	Female	70	10	Master	No
	9	Registered nurse	Female	62	40	Bachelor	No
	10	Speech pathologist	Female	32	9	Bachelor	No
Group 2	ID	Carer role	Gender	Age, years	Family role in taking care of their family with dementia, years		
Family carers	1	Daughter	Female	40		2	
	2	Husband	Male	75		6	
	3	Wife	Female	67		5	
	4	Daughter	Female	45		5	
	5	Daughter	Female	39		5	
	6	Daughter	Female	45		5	
	7	Daughter	Female	37		8	

(Continues)

TABLE 1 | (Continued)

Group 3	ID	Gender	Age, years	Diagnosis of dementia	Years of dementia diagnosis
People living with dementia	1	Male	69	Young-Onset Dementia, Frontotemporal dementia	10
	2	Female	67	Other types of dementia	8
	3	Male	77	Other types of dementia	Not available ^a
	4	Female	78	Alzheimer's disease	7
	5	Female	70	Alzheimer's disease	10
	6	Female	81	Not available ^a	Not available ^a

^aNot available: The data was not available in the StepUp platform where participants were recruited.

TABLE 2 | Themes and subthemes developed from interviews with healthcare professionals, families, and people with dementia.

Themes	Subthemes
1. Communications to identify pain in people with dementia	Communication with people with dementia Communication with informal and formal carers Communication strategies for pain identification
2. Pain assessment in people with dementia	Indicators of pain in dementia The use of pain assessment tools Personalised approach to pain assessment
3. Pain management strategies	Effective nonpharmacological strategies Challenges and side effects of using pain medications
4. Training in pain and dementia care	A lack of training in pain and dementia care Preferred features of a staff training program

pain and dementia care and a preferred training programme prototype, such as a self-paced online short course with small chunks of different modules, were identified.

4.1 | Theme 1 Communications to Identify Pain in People With Dementia

4.1.1 | Subtheme 1.1: Communication With People With Dementia

Healthcare professionals and family carers identified challenges in communicating with people with dementia. This occurs in particular when people with advanced dementia lose the ability to communicate and cannot describe their pain experience, including location, type, and severity. It can be challenging to distinguish pain from other uncomfortable experiences. Moreover, people with dementia mentioned their experience of pain sometimes being ignored by healthcare professionals, and they found it challenging to convince carers to acknowledge their pain experience. The following quotations demonstrate such challenges.

I think their ability to communicate reliably is a big challenge. So, in those with more advanced stages of dementia, they are losing their ability to communicate and then they can not necessarily tell us where the pain is, what type of pain, or how severe it is. They may be telling us something that is not reliable.

(Healthcare Professional ID 10, Speech Pathologist)

I don't know if it's genuine pain or if he is uncomfortable with something, but he can't describe it. It's hard. Sometimes, he would say ouch, like making noise or grimacing. But I can't really verbalise it so it's hard to know sometimes if he's in pain or not.

(Family Carer, ID 7)

That inability to understand the chronic nature of the back pain made me so frustrated with the medical professions. I had one GP tell me that people with dementia don't experience pain.

(Person with Dementia, ID 2)

4.1.2 | Subtheme 1.2: Communication With Informal and Formal Carers

When people with dementia are not able to communicate, both informal (e.g., family carers) and formal carers, who are familiar with the care recipients, are interviewed when conducting pain assessments—as it is assumed that these people know the person with dementia and can identify changes that could be pain-indicative. Familiarity is a significant facilitator for pain assessment in people with dementia, and it is helpful when healthcare professionals spend time with family carers discussing the patient's history to encourage familiarity. Family carers reported that healthcare professionals should spend more time with people living with dementia so they can identify changes. In addition, healthcare professionals rely on other staff members and families who have a significant care role for the person with dementia to identify the person's history, such as what is expected and abnormal for the person and to plan pain management strategies. Moreover, they reported the importance of communicating with nurses and general practitioners during pain assessment and management.

I think engaging the family is often really helpful cause they know what the patient does when they are in pain. They know the type of pain that the patient normally has, so that is definitely a really big facilitator.

(Healthcare Professional ID 10, Speech Pathologist)

I think it's very important because the family know the person better than you do, especially when I was in the consulting role, and I did not know the person at all. So, I have to rely on what the family were telling me about. How the person normally was to see if there was a change.

(Healthcare Professional ID 7, Registered Nurse)

I did the agency nurse for quite a long time, but often, I don't know the person at all or on all. I've only met them once or twice, so I do have to rely on the regular staff telling me that this is normal for this person or

this is abnormal for this person. So, I do need to rely on what we call third-party evidence.

(Healthcare Professional ID 8, Clinical Nurse Educator)

Generally communicating with nurses on the floor. If I go and assess pain for a patient that, I know they are in pain, and I'll do a head-to-toe assessment because, as we know, elderly patients could have wounds, or leg ulcers. In fact, you know, pressure areas, it's looking at the skin inspection and all that, too. So, I'll talk to other nurses as well. I'll communicate with the nurses and the doctors, and we'll all come up with a plan.

(Healthcare Professional ID 9, Registered Nurse)

I would like lower ratios so that the nurses, instead of however many patients that they've got, that there's more nurses to less people so that they get to know the people, so that they can say this is not right for this person. This person usually reacts in this way. When I come in the room or get their food or whatever. But today, they're not reacting that way. So, they have the time and the personal experience with that patient to pick up on that. Because it may not be like a groan or like just, you know, verbal or whatever, it may just be something different that they notice about their patients because they spend so much time with them and they don't move around different patients all the time. Staying patient to know them better.

(Family Carer, ID 1)

4.1.3 | Subtheme 1.3: Communication Strategies for Pain Identification

Healthcare professionals highlighted the importance of directly communicating with people with dementia to identify pain and to remind them that this was a person and not just a pain diagnosis. Helpful strategies included framing simple questions tailored to their level of communication ability and using alternative words, such as discomfort and aching, instead of pain. Family members also used alternative words to identify pain. A speech pathologist (Healthcare Professional ID 2) stated that “not everyone responds to the word pain, depending on their personality.” Additionally, healthcare professionals focused on pain signals and continued their communication by exploring observed signals.

You ask them a question that is tailored to their level of communication ability. It may be as simple as “Are you in pain?” So give them that yes or no response or if they are able to give you a little bit more information, that they can tell you more detail at where is the

pain, but usually keeping it very simple and if they are localising towards a certain body part, asking them like “Is it your arm sore?” or to try and ascertain exactly where the pain is.

(Healthcare Professional ID 10, Speech Pathologist)

So, I will say, have you got pain in the face? Have you got pain in the neck? Have you got pain in the shoulders? And that the arms, the back, the legs and tummy, the chest. So, I'll do a full-body scan and each part. She will say yes or no, and it doesn't say that first time. I just stick to that part, and I'll translate in different way like have you got back pain, I said have you got a sore back and if she doesn't, Yeah, I said. Well, have you got an aching back? Just has the words around a little bit. So, if I don't get an answer. I will keep going around the body, and we'll come back to that body part.

(Family Carer, ID 2)

4.2 | Theme 2 Pain Assessment in People With Dementia

4.2.1 | Subtheme 2.1: Indicators of Pain in Dementia

Healthcare professionals reported that they often focused on nonverbal cues, such as aggressive behaviours, anxiety, wandering, facial expressions (e.g., grimacing), body language, and vocalisations, as indicators of pain in people with dementia. They also observed pain-related injuries and changes in sleep, eating, and walking patterns for background information. Similarly, family carers focused on unusual behavioural signs and facial expressions as indicators of pain.

So, to be a detective and look out for those non-verbal cues. Is the person not sleeping as well? Are there changes in their behaviour? Are they aggressive? Are they anxious? Are they wandering?

(Healthcare Professional ID 4, Dementia Support Specialist)

Using the patient's facial expressions and body language to interpret if they might be in pain. So, if they are grimacing or vocalising in a way that might be indicating that they are in pain or discomfort, or often they will grab the part of their body that is in pain.

(Healthcare Professional ID 10, Speech Pathologist)

So, there are signs like behavioural signs that is indicating she thinks it is bad. So that is like a behavioural issue or an indicator to me that maybe she is not well, like when there is unusual behaviour, and then you have to understand what unusual behaviour is.

(Family Carer, ID 6)

4.2.2 | Subtheme 2.2: The Use of Pain Assessment Tools

Some healthcare professionals use self-reporting scales, such as the Wong-Baker Face Scale or numeric rating scales. Among these, three healthcare professionals reported their preferences for using the Wong-Baker Face Scale as they found that the visual face images were easy to understand. Additionally, some observational scales, such as the Pain Assessment in Advanced Dementia (PAINAD) (Warden et al. 2003), the Abbey Pain Scale (Abbey et al. 2004), and the PainChek app, were used as a guide to assess pain for people with dementia in clinical practice, especially by new staff or carers. However, the limitations of these scales were mentioned, including the ambiguity and challenges of involving people with dementia in their subjective reporting. Moreover, a dementia support specialist highlighted the importance of communicating and working directly with the person with dementia rather than just relying on tools. Healthcare professionals also reported that the observation skills and experiences of working with people with dementia are underestimated.

I think that is very ambiguous anyway and often hard for someone with dementia. And it is so subjective anyway. But yeah, I guess I personally don't, but I see some tools get used occasionally, but not super routinely, I would say on the aged care ward. I think the main barriers would be that it can be a bit ambiguous, hard to get the patient sometimes to participate in it. I think sometimes I think just staff aren't well-trained in the area.

(Healthcare Professional ID 3, General Practitioner)

They are non-verbal, but if they are verbal. Yes, of course, that is the first thing you do. You ask them if they are in pain and. Ask them to point or show you where the pain is, and you can also tell by body posture and behaviour. So, if they are guarding a body part like they're holding their and total regional. They're holding their knee, and you are asking something that where it hurts. And we do, I like to use the Wong Baker faces scale. I find that's better than the numeric 0 to 10, some people with dementia are capable of that. Yeah, I wanna start more to 10. How bad was the pain that you can still use that, but the Wong Baker I like a lot. So, every facility has it's here on the wall and the nurses' station, so you take the chart down and you sit down beside the person and you point to the face. And then ask them where and how does the pain feel? If this was your little picture, what would you say, and I'll point to the picture.

(Healthcare Professional ID 8, Clinical Nurse Educator)

I think we rely too much on the tools and not actually work directly with the person. They've got a score it's not high enough to be pain, but when you actually

looking at the person and talking to the person and observing them, it is pretty obvious that they've got pain. I think we underestimate sometimes our observation skills. Especially when you work with the same people for a number of years, I couldn't physically see anything, but you just know them from their usual, you just know when they're not well, which is hard if you're a new nurse or a new carer that hasn't gained that experience. And that's where tools certainly can help, but I wouldn't like to see a system where it's just completely reliant on tools.

(Healthcare Professional ID 4, Dementia Support Specialist)

A clinical nurse educator highlighted the need to develop some up-to-date and more user-friendly tools that could combine personal assessment and information from both the people with dementia themselves and the people who know them.

The other problem, I think, is just the lack of any kind of better assessment tools or a combination of tools and I prefer to use a combination of personal assessment, talking to people who know the person, talk to a person themselves. It would be nice if those things could be put together in one more comprehensive tool.

(Healthcare Professional ID 8, Clinical Nurse Educator)

4.2.3 | Subtheme 2.3: Personalised Approach to Pain Assessment

Healthcare professionals and family carers highlighted the need for familiarity with the person with dementia to facilitate personalised pain assessment depending on their usual behaviours. They also reported on the need to understand the different stages and types of dementia and to consider these when undertaking pain assessment.

Being able to identify pain in a person with dementia is knowing that person, like being familiar with the person, that the behaviours identified on scales could actually be because of other factors, not just pain. They might be upset or angry or frustrated, or they could be hallucinating. So being familiar with the person knowing what their steady state is, knowing what they're like. And how they present normally in their usual sense, I think that's very important but it's difficult.

(Healthcare Professional ID 6, Registered Nurse)

I think probably one of the things is to have familiarity. It's quite important. So, when you're using services like that (I know it's not always

possible), have the same people so they know how she (her Mom, who has dementia) gets along with them.

(Family Carer ID, 1)

4.3 | Theme 3 Pain Management Strategies

4.3.1 | Subtheme 3.1: Effective Nonpharmacological Strategies for Pain Management

Participants initially used nonpharmacological strategies as the first-line therapy to manage pain. These strategies included massage, heat packs, aromatherapy, light exercises with a range of movements, distraction, reminiscence therapies, showers, repositioning, and acupuncture. These strategies provided comfort to people with dementia in pain. If no progress was observed, participants resorted to pharmacological strategies. People living with dementia, as well as family carers, stated that they use non-pharmacological strategies, such as distraction, massage, and heat packs, to relieve pain. They also verbalised the effectiveness of these strategies.

Holding their hand, talking to them, taking them for a little walk, looking at things. So, taking them to their room. Looking at pictures of their wedding or pictures of their children or talking with them about their past. Something that is meaningful.

(Healthcare Professional ID 7, Registered Nurse)

If the patient is experiencing pain because of the position, just adjusting that position to make them more comfortable. Making sure that they are being moved regularly to avoid any sort of pain from pressure injuries. We did also have a diversional therapist up on the ward for quite some time who was doing some really good work with these patients as a way of distracting them in order to reduce the focus that they had on the pain.

(Healthcare Professional ID 10, Speech Pathologist)

I tried to distract myself with other things. I've got dogs. I've got my birds. I spend a lot of time with them. I've got probably eight birds. Conyers and cockatiels. They are a very good distraction that helps at times.

(Person with Dementia, ID 4)

The only other thing is he doesn't seem to like the cold, so when he says yes, I want something warm, like heat packs on specific areas. And he likes massage. So, if you give massage, he enjoys that. But he doesn't really like cold packs.

(Family Carer, ID 5)

4.3.2 | Subtheme 3.2: Challenges and Side Effects of Using Pain Medications

The challenges of using pain medications for people living with dementia were highlighted, including the low compliance of taking medications due to polypharmacy and the risk of being under-treated or over-treated with pain medications. Reported side effects of pain medications included reduced appetite, constipation, drowsiness, delirium, increased fall risks, and drug dependence. Therefore, some healthcare professionals were reluctant to prescribe pain medications, in particular opioids, to manage pain in people with dementia. Additionally, conflicts with family carers were often reported when prescribing medications. Family members were unhappy to provide pain medications.

You should be very careful because of the issue around polypharmacy. A lot of pain relief can cause constipation. And if you give them too much pain relief that they become really drowsy or something that will increase their falls risk and obviously they're not going to eat very well and then combine all of that together, polypharmacy and drowsiness and all that kind of things can make delirium risk increase.

(Healthcare Professional ID 3, General Practitioner)

'We mustn't give mum morphine because she'll become addicted'. That's a common thing you might hear, and, of course, that's really not very sensible at all because if the person is experiencing pain. So, if we need those sorts of drugs to manage, for example, end-of-life, cancer pain, then I'm going to discuss them with the doctors. And sometimes you will find family members are very, very resistant to that.

(Healthcare Professional ID 7, Registered Nurse)

I'm probably not happy with the pain medication, but maybe it's something I can discuss here, geriatrician, because she's like deteriorating quite a lot. And I think it's getting close to the end, but it might be worth looking at the pain management a bit better.

(Family Carer, ID 2)

4.4 | Theme 4 Training in Pain and Dementia Care

4.4.1 | Subtheme 4.1: A Lack of Training in Pain and Dementia Care

Negative attitudes and stigma towards aging and dementia were reported. In particular, people with dementia highlighted that health professionals had limited training in communication, a

lack of understanding, and limited knowledge of dementia care. Healthcare professionals noted that family carers and junior staff might lack sufficient knowledge. Both healthcare professionals and family carers expressed the need for education in several areas, including pain assessment and pain management strategies.

I think pain is such an individual thing. Maybe there could be some training. I think if they know somebody has something. And I'm not all for taking medication all the time, but you could ask. Have you got any pain? What number is your pain? I think that training would be useful to communicate.

(Person with Dementia, ID 5)

I can't live in your shoes to understand it. It does make you frustrated at times. It makes you depressed at other times because you feel like you're living in your head trying to deal with your pain. It's just this total lack of understanding and knowledge, so I've sort of been part move from doing a lot of advocacies about my problem.

(Person with Dementia, ID 2)

It's just an educational gap that we try to address with the family members and another challenge, I suppose, is with more junior staff. And members of the MDT that maybe haven't got a good knowledge base.

(Healthcare Professional ID 2, Clinical Nurse Educator)

Definitely for our staff. Like again I think it just needs to be across all levels of staff like nursing, medical and allied health. I think education around making sure that they know what is appropriate pain relief for people, thinking about that sort of side effects and polypharmacy and what it can mean. And then the signs of how to look out for things and then even just to sort of flag with them like that whole idea.

(Healthcare Professional ID1, Speech Pathologist)

Because I've had this conversation that with many nurses on the floor, they'll say, well, I offered them pain relief and they said no or they don't realise that it should be given regularly as a preventative. And I have this conversation with the pharmacist, and he said that's a good one, because if they're not consenting to analgesia, where does that stand legally because they've declined the analgesia, and how do we get around that? And I said well, it depends on their capacity, doesn't it? So yeah, more education analogies in the elderly would be great.

(Healthcare Professional ID10, Speech Pathologist)

It would be good to have knowledge about it. Probably like recognising pain signs at the start and then probably like some general techniques that might not involve medication and then maybe then talking to the doctors about putting in place and management plan in terms of what medications?

(Family Carer, ID 2)

4.4.2 | Subtheme 4.2: Preferred Features of a Staff Training Program

The preferred training program prototype includes self-paced, online, short courses with small chunks of different modules. The format of the training resources should engage learners and be easy to navigate with multi-modal resources, including text, video, audio, case studies, resources with links, people with lived experiences, quizzes, and activities. The suggested contents included (1) knowledge of pain in dementia, (2) pain recognition and assessment tools, and (3) communication and family involvement. Moreover, training programs tailored to the needs of different groups, including people with dementia, family carers, students, and healthcare professionals from different backgrounds, are needed to address the challenges of effective pain management in people with dementia. A healthcare professional (General Practitioner ID 3) suggested, “Have it online, self-paced that is flexible and easy to access. The healthcare professionals can revisit the content of the course anytime and can do it at their own pace”. Family carers reported that more training is needed regarding how to recognise pain for people with dementia, some general non-drug techniques, as well as communication with healthcare professionals regarding a pain management plan. For example, a family carer (Family carer ID 2) suggested the content should be, “Probably like recognising pain signs at the start and then probably like some general techniques that might not involve medication and then maybe then talking to the doctors about putting in place a management plan.” A clinical nurse consultant was more prescriptive regarding the type of education materials required.

Multi-modal learning resources. It makes obviously more interesting if you've got videos to watch and you know different websites to link into, best practise information, access to sort of research papers. Having a sort of a variety of different knowledge, patient experience videos or vignettes is always very helpful.

(Healthcare Professional ID 2, Clinical Nurse Consultant)

5 | Discussion

This study reports the perspectives of people living with dementia, their family carers, and healthcare professionals in pain assessment and management for people living with dementia. Pain has a negative impact on the physical, psychological, and

social well-being of individuals. However, people with dementia, family carers, and healthcare professionals highlighted that the assessment and management of pain in residents with dementia are challenging tasks. Facilitators to mitigate these challenges included (1) collaborative communication among people with dementia, families, and healthcare professionals; (2) pain assessment with a user-friendly tool that considers a personalised approach to identify changes in non-verbal and behavioural cues; and (3) knowledge and training to enhance pain assessment skills.

5.1 | Collaborative Communication Among People With Dementia, Families, and Healthcare Professionals

Pain recognition involves investigating pain-related cues and behaviours to inform healthcare decision-making (Dowding et al. 2016). While verbal communication deteriorates with cognitive decline, non-verbal cues become increasingly important; therefore, it is important to identify non-verbal cues combined with unusual behaviours while assessing pain in people with dementia. Healthcare professionals collected information to create a comprehensive picture of pain identification in people with dementia. Nevertheless, this process is perceived as intricate and associated with significant uncertainty (Bullock et al. 2020; Gilmore-Bykovskiy and Bowers 2013). For instance, healthcare professionals often struggle to differentiate between behavioural and non-verbal cues that may indicate pain or non-pain-related distress as well as behavioural and psychological symptoms of dementia.

Communicating pain in individuals with dementia remains a complex challenge. Therefore, family carers play a crucial role in pain assessment for individuals with dementia. They often spend the most time with the person and are in the best position to detect subtle changes in behaviour or mood indicative of pain (Bullock et al. 2020). Therefore, the familiarity of family carers was identified as a facilitator of pain assessment. Family carers, on the other hand, experience difficulty in attributing behaviour changes to a pain experience. However, healthcare professionals identified the need for communication with family carers to support pain identification in people living with dementia.

Healthcare professionals could be vigilant in observing and interpreting these non-verbal signals. First, healthcare professionals need to spend more time with people living with dementia to be able to observe subtle changes in their behaviours. Communication with other staff members (such as nurses or general practitioners) could also support the identification of behavioural change and improve pain management for people living with dementia. However, pain information elicited by various healthcare staff at different times using diverse methods was fragmented in paper-based documentation (Lichtner et al. 2016). To address this challenge, a multidisciplinary approach, which includes general practitioners, geriatric specialists, psychologists, registered nurses, pharmacists, dementia care specialists, and palliative care experts, is needed to address pain in dementia effectively (Jennings et al. 2018; van Kooten

et al. 2015). Moreover, this holistic approach ensures that the unique needs of people with dementia are considered and that their pain is managed comprehensively.

Research has emphasised the importance of family communication with healthcare professionals to share observations and collaborate on pain management strategies (Pu et al. 2023; Riffin et al. 2022). However, they have limited pain identification and management support for people living with dementia. Furthermore, family carers are generally not acknowledged as key pain management care planners and decision-makers. In addition, families are repeatedly excluded from knowledge exchange, care planning, and decision-making regarding pain management (Lundin and Godskesen 2021). Despite policy initiatives recommending partnerships with family carers to achieve high-quality and sustainable care (Häikiö et al. 2020), limited guidance and research are available on how families of people living with dementia can be involved in pain management. Family carers lack support in pain assessment, pain management, and medication administration to better care for people living with dementia (Bullock et al. 2020). As a result, there remains much to be understood about optimising support for family care in pain management for people living with dementia. By acknowledging and addressing the unique challenges in communicating pain in people living with dementia, family carers and healthcare professionals can work together to enhance the comfort and well-being of those in their care, thereby promoting dignity and reducing suffering.

5.2 | A Personalised Approach for Pain Assessment

Currently, there is no gold standard tool for assessing pain in people living with dementia due to limited evidence regarding the reliability, validity, and clinical utility of existing tools (Lichtner et al. 2014). However, despite these limitations, pain assessment tools are widely used in this population. One reason for their continued use is simplicity and feasibility. For instance, the developers of the Abbey Pain Scale suggest that it can be completed within one minute (Abbey et al. 2004). Second, current recommendations support their use (Felton et al. 2021). For example, the UK National Guidelines (2018) recommend the use of PAINAD for individuals with advanced dementia (Schofield 2018). Third, their integration into institutional protocols and familiarity among carers further reinforce their continued use (Lichtner et al. 2014).

However, a personalised pain assessment approach that integrates input from both people with dementia and the people who know them well is highlighted. To achieve this, a multimodal method that integrates behavioural observations, physiological indicators, and insights from caregivers and people living with dementia needs to be considered (Wideman et al. 2019). Moreover, existing tools rely on generalised pain indicators, which may not align with individual baseline behaviours. Improved tools could establish personalised nonverbal and behavioural baselines using routine movement data. Additionally, continuous pain monitoring through wearables or facial recognition can track fluctuations over time, enabling early intervention (Xu and Sa 2021). However, ethical

considerations, including privacy protection, must be addressed when implementing such technologies (Prkachin and Hammal 2021).

5.3 | Need for Further Training and Support for Healthcare Professionals and Families

Our study identified a lack of knowledge and training in pain and dementia care. Both healthcare professionals and family carers expressed the need for education in several areas, including pain assessment and pain management strategies. People with dementia also highlighted that health professionals had limited training in communication, a lack of understanding, and limited knowledge of dementia care.

One training need identified in our study is education on pain assessment tools. Similarly, a review reported that nurses need to be trained in using pain assessment tools for people living with dementia (Jonsdottir and Gunnarsson 2021). Additionally, the study participants found that the current tools poorly involve people with dementia and lack sufficient clinical utility in daily practice. One reason for poor clinical utility could be the lack of training on pain assessment tools' use. Therefore, it is important to provide training on the utility of pain assessment tools to enhance their use in everyday clinical practice.

Pain management strategies were another training area that healthcare professionals and family carers identified in our study. Carers and healthcare professionals were not satisfied with pain management for people with dementia. There were disagreements about the best treatment options partly due to a lack of proper training and understanding of pain management (Smith et al. 2023). Similarly, in our study, healthcare professionals verbalised that family carers resist some pain management strategies.

Healthcare professionals can receive online training that is more convenient, flexible, and accessible. For example, people can access it when and where they want, for example, via smartphones, tablets, or computers. In addition, using novel technologies such as integrated learning platforms, digitalised animations, and virtual simulation with formative assessment can improve user experience and engagement (Muirhead et al. 2022). An increased emphasis on education for healthcare professionals should be prioritised as a key action in the 2021 National Strategic Action Plan for Pain Management (Australian Government Department of Health 2021). Therefore, an online interdisciplinary training program is essential to enhance healthcare professionals' collaborative practice in timely and effective pain assessment and management for people with dementia.

5.4 | Strengths and Limitations of the Research

The study involved people living with dementia, family carers, and healthcare professionals from various backgrounds, enhancing the richness of the data. The inclusion of different stakeholders is a strength as it improves the inclusion of

unique perspectives (Maurer et al. 2022). Codes and themes were developed and refined using an iterative team approach to improve rigour (Cassell and Symon 2011). Most study participants were people who had lived experience of dementia or who were taking care of people with dementia. Despite an attempt to maximise participants' backgrounds, remote participant recruitment and data collection might have prevented some eligible people from participating, for example, due to difficulty with access to the internet or using online platforms. We conducted both online and telephone interviews. Due to the differences in data collection methods (e.g., online and telephone interviews), it was complex to gauge nonverbal cues, and therefore, we did not analyse nonverbal cues. Although it has been suggested that it can be challenging to establish rapport during telephone interviews (Drabble et al. 2016), we did not find that the telephone interviews challenged participants. This study included six people with early-stage dementia who could provide informed consent in English. The small sample size may limit the reliability of their specific perspectives and reduce the applicability of the findings to a more diverse population, including those with severe communication barriers. We did not perform a formal cognitive function assessment or hearing or vision tests before the interview. However, we explained the study aims and obtained both verbal and written informed consent from participants. Moreover, people with dementia and family carers who could not speak English were excluded from this study.

5.5 | Recommendations for Further Research

Timely and appropriate pain management is integral to ensuring high standards of care and quality of life for people with dementia, starting with pain assessment; however, healthcare professionals often lack education, support, and training to ensure that pain-related needs are addressed. Implementing regular training programmes focused on pain assessment and management for people living with dementia, including pain assessment tools' use, could address this. More research is needed to offer easy-to-access and concurrent specialised training to enhance healthcare professionals' knowledge, attitudes, and practice in pain assessment and management. This has the potential to lead to improved interdisciplinary and person-centred clinical assessments of pain among people with dementia. This, in turn, will lead to a reduction in the silent suffering and unrecognised pain among people with dementia. Additionally, developing standardised communication protocols may ensure consistent and accurate pain assessments. Moreover, fostering interdisciplinary communication by organising regular team meetings and case discussions could enhance collaboration between family carers and healthcare professionals. Future research should explore the effectiveness of such strategies to overcome challenges in pain assessment and management in people living with dementia.

5.6 | Implications for Policy and Practice

We aim to ensure that health professionals know how to assess pain in people with dementia. Furthermore, we aspire to equip healthcare professionals with online education to improve

their pain assessment knowledge, attitudes, and practice. Implementing targeted education programmes may help improve pain assessment by healthcare professionals. Additionally, education programmes should be implemented to enhance family carers' knowledge. This will enhance family involvement and open communication during pain assessment and management for people living with dementia. Ultimately, we aim to inform policymakers of the potential of educational programmes to influence policies and increase government funding support to encourage regular pain assessment and better pain management plans for people with dementia.

6 | Conclusions

Both healthcare professionals and family carers found it challenging to assess and manage pain in people with dementia mainly due to communication barriers and lack of skill training. Further training programmes are needed to enhance pain assessment and management for people with dementia.

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Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.