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Barriers and strategies for pain management in non-verbal people with dementia in residential care facilities: protocol for an e-Delphi study

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ABSTRACT

Introduction Pain is a prevalent symptom in people living with dementia. Evidence shows that pain frequently remains unrecognised and untreated in this vulnerable population, leading to avoidable suffering. Effective pain management is hindered by multifactorial barriers at the individual, organisational and policy level. This study aims to achieve expert consensus on the key barriers to pain management in non-verbal people living with dementia and strategies to address these barriers within Portuguese residential care facilities.

Methods and analysis An e-Delphi study will be conducted using two rounds of online questionnaires. The Behaviour Change Wheel (BCW) framework guided the development of e-Delphi statements by linking identified determinants (i.e., barriers and facilitators) to intervention functions. Barriers were extracted from the literature reviews and mapped into the capability, opportunity and motivation–behaviour model. Intervention functions were then selected using the BCW linkage matrices and operationalised into practical strategies. A purposive and snowball sampling approach will be used to recruit a heterogeneous panel of experts across national residential care facilities, including nurses, physicians, managers and policymakers with relevant experience in dementia. During the e-Delphi rounds, participants will be invited to rate the relevance of each barrier and associated strategy(ies) on a five-point Likert scale and provide comments or suggestions. Consensus will be defined as ≥75% agreement on each statement.

Ethics and dissemination Ethical approval for this study was obtained from the Egas Moniz Ethics Committee (Ref. 1586), and all procedures will comply with the Declaration of Helsinki. Informed consent will be obtained from all participants. The findings will be disseminated through a peer-reviewed publication, scientific events and stakeholder networks, including residential care facilities, to inform future practice and policy in dementia care.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This study applies a structure and theory-informed approach using the Behaviour Change Wheel to ensure the systematic identification and linkage of behavioural determinants to intervention strategies.
⇒ Recruitment of a heterogeneous expert panel across multiple professional groups enhances the relevance and applicability of findings to diverse residential care facilities.
⇒ The study protocol was informed by the accurate consensus reporting document reporting guidelines, ensuring transparency and methodological integrity.
⇒ The use of purposive and snowball sampling may limit generalisability due to potential selection bias and reliance on expert opinion.

INTRODUCTION

Globally, around 50 million people live with dementia and projections suggest an increasing prevalence due to the ageing population.[1] By 2050, the number of individuals affected by dementia is expected to triple.[2] Dementia poses a significant economic burden, with global costs estimated at US$1313.4 billion in 2019[3] and projected to exceed US$2 trillion by 2030.[4] In Portugal, over 193 000 people live with dementia, generating the costs of approximately €2 billion—equivalent to 1% of the national gross domestic product.[5]

Pain is a prevalent symptom experienced by people living with dementia. A systematic review shows that 10%–80% of people living with dementia experience acute or chronic pain, with higher prevalence among those with moderate to severe dementia.[6]

Evidence shows that pain frequently remains unrecognised and untreated in people with dementia, leading to avoidable suffering.[7] In American nursing homes, a study involving 50 673 residents found that those with dementia were provided with fewer pain assessment and less pharmacological and non-pharmacological treatment compared with those without dementia.[8] Evidence points to disparities in pain treatment, with people with dementia receiving pain medication less often than others.[9] Silent pain not

only causes avoidable suffering in people with dementia but also contributes to behavioural symptoms, such as agitation and aggression. These symptoms often lead to inappropriate use of psychotropic medication, including atypical antipsychotics, which are associated with a higher risk of mortality in people with dementia.[10 11]

Several barriers contribute to the problem of unrecognised and untreated pain in people with dementia. From an assessment perspective, challenges often stem from cognitive decline and communication difficulties in this population,[12] as well as the limited availability of reliable and objective pain assessment tools for people with dementia.[13] Additional barriers frequently reported in the literature include knowledge gaps among professionals and concerns regarding the use of analgesics.[14]

Addressing these challenges requires the development of evidence and theory-based interventions that target the specific barriers to pain management in non-verbal people with dementia at an individual, organisational and policy level.

A meta-analysis of six randomised controlled trials on interventions to improve pain management in people with dementia in residential care facilities and emergency departments showed limited positive effects.[15] Notably, none of these interventions combined evidence and theory to the development process, potentially missing out on addressing comprehensive pain management barriers, which can influence the outcomes. The literature reports that the absence of a theoretical underpinning is associated with limited success in behaviour change interventions.[16]

This study is a part of a larger project that aims to develop a behaviour change intervention targeted at professionals to improve pain management in non-verbal people with dementia. Specifically, it aims to achieve consensus on barriers to pain management in non-verbal people with dementia in Portuguese residential care facilities and strategies to address these barriers, supporting the development of the evidence and theory-based intervention.

METHODS AND ANALYSIS

Study context

In Portugal, available estimates suggest that between 29% and 78% of people with dementia reside in residential care facilities, although empirical data on institutionalisation remain scarce.[17 18] Residential care facilities are defined as collective accommodation units, either temporary or permanent, primarily intended for older adults (aged 65+).

In Portugal, these facilities operate under the jurisdiction of the Ministry of Labour, Solidarity and Social Security and are a part of the social care sector. They may be managed by private non-profit institutions or private for-profit providers.[19] Portuguese residential care facilities are mandated to comply with national regulatory standards concerning infrastructure, staffing ratios and care protocols, as established by the Social Security and Health Authorities. Staffing requirements are determined based on the residents' level of functional dependency, with institutions expected to provide continuous care accordingly. For example, in settings accommodating residents with low dependency, the stipulated ratio is 1 nurse per 40 residents; for those with high dependency, the ratio increases to 1 nurse per 20 residents. Notably, the presence of nursing professionals is not required on a 24/7 basis. Instead, direct care is delivered primarily by nurse assistants working in rotating shifts. Additional professionals, such as physiotherapists, physicians and volunteers, may also be included in these settings; however, their participation is not mandated by current regulation.[20] Table 1 shows the recommended staffing ratios, professional qualifications and workload specifications for the national context, according to the level of resident dependency.

Study design

The Delphi technique will be employed to address the study aim. The Delphi technique is a research method for achieving consensus among key experts and stakeholders within a particular field, through a multistage process of sequential rounds.[21] Through the feedback mechanism, reconciliation of differing experts' perspectives is facilitated, mitigating the influence of dominant individuals and minimising power imbalances that may occur in face-to-face communication between participants.[22 23] This protocol for the e-Delphi study was informed by the ACcurate COnsensus Reporting Document (ACCORD) reporting guidelines.[24]

Figure 1 presents an overview of the e-Delphi study. In this study, the first round—typically consisting of an open-ended questionnaire to generate items—was replaced by a literature review. This decision was based on the availability of empirical evidence that has already synthesised known barriers and facilitators to pain management in non-verbal people living with dementia. Drawing on the research team's previous experience in Delphi studies[25–27] and considering the available resources, two rounds were deemed appropriate to build consensus and meet the overall objectives of the larger project.

Theoretical framework

The Behaviour Change Wheel (BCW) will be adopted to guide the e-Delphi statements development. The BCW is a comprehensive framework designed to develop behaviour change interventions. Through a systematic and structured process, the BCW enables the theory and evidence-based selection of intervention components, ensuring that the intervention targets the underlying determinants of behaviour.[28] The framework consists of three interrelated layers: the capability, opportunity and motivation–behaviour (COM-B) model, intervention functions and policy categories.

At the BCW core is a model of human behaviour—the COM-B—which posits that behaviour (B) is driven by three interacting components: capability (C), opportunity (O)

Table 1 Staffing ratios, required training and workload for low and high dependency residents in residential care facilities in Portugal[20]

	Professional	Ratio	Training	Workload
Low dependency residents	Director	1 per facility	Social sciences, health or social services degree	Part time (≤30 residents: 50%)(≤15: 3 h/day)
	Sociocultural animator/geriatric technician	1 per 40 residents	Not specified	Part time (not defined)
	Nurse	1 per 40 residents	Nursing degree	Part time (not defined)
	Nurse assistants	1 per 8 residents (day) 1 per 20 residents (night)	Not specified	Full time (day and night)
	Housekeeping supervisor	1 per facility	Not specified	Full time (≥ 40 residents)
	Cook/kitchen assistant	1 per facility 1 per 20 residents	Not specified	Part time (outsourced if required)
	Auxiliary worker (eg, bus drivers and security guards)	1/20 residents	Not specified	Part time (outsourced if required)
High dependency residents	Nurse	1 per 20 residents	Nursing degree	Part time (not defined)
	Nurse assistants	1 per 5 residents	Not specified	Full time (day and night)
	Auxiliary worker (eg, bus drivers and security guards)	1 per 15 residents	Not specified	Part time (outsourced if required)

and motivation (M). Capability refers to an individual's *psychological* and *physical* abilities to perform a behaviour, encompassing skills and knowledge. Opportunity encompasses external environmental factors that may facilitate or hinder the behaviour, including the *physical* and *social environment*. Motivation aggregates both *reflective* and *automatic* mental processes that energise and direct behaviour, such as the individual's goals, plans and beliefs along with habits or impulses.[28 29]

The second layer of the BCW outlines nine intervention functions, defined as 'broad categories of means by which an intervention can change behaviour'.[28] Examples of intervention functions include *education, persuasion, incentivisation* and *training*.

The outermost layer consists of seven policy categories, which represent higher level strategies for supporting and enacting the interventions by authorities. These include *communication*, *guidelines*, *regulation* and *service provision*. Policy categories play a crucial role in creating structural conditions that facilitate sustainable behaviour change at the individual or population level.

The BCW facilitates a stepwise approach to (1) understanding the behaviour through the COM-B model, (2) identifying appropriate intervention functions and (3) selecting policy categories via an established link between these three elements, as prescribed by the authors.[28]

For this study, we addressed only the first step—understanding the behaviour—and the second step—identifying intervention functions—as a basis for developing the e-Delphi statements, as the policy categories fall outside the scope of this exercise.

Statement development for the first round

Step 1: understanding the behaviour

The first step in the process involved understanding the key determinants of pain management (ie, barriers and facilitators), including pain assessment and treatment, through a literature search conducted in May 2025. The inclusion criterion was reviews of studies reporting on pain management determinants in non-verbal people living with dementia or individuals with dementia in residential care facilities or other settings. There was no restriction regarding the year of publication or language. Editorials, commentaries, case studies, research protocols, summaries and conference proceedings were excluded.

A search was performed in PubMed. A search strategy was developed with the following keyword and terms: (pain assessment OR pain treatment OR pain management) AND (facilitator OR barrier OR difficult OR determinant) AND (dementia OR Alzheimer). PubMed filters were applied: review, systematic review and meta-analysis.

Records were screened by title and abstract by one reviewer (IBF) from the search results. A total of 340 records were excluded. Five reviews were selected for full-text screening and included for data extraction as they met the inclusion criteria.[30–34] The characteristics of the five included reviews are presented in table 2.

The determinants were extracted and compiled into a list of barriers and facilitators by a reviewer (IBF). Data

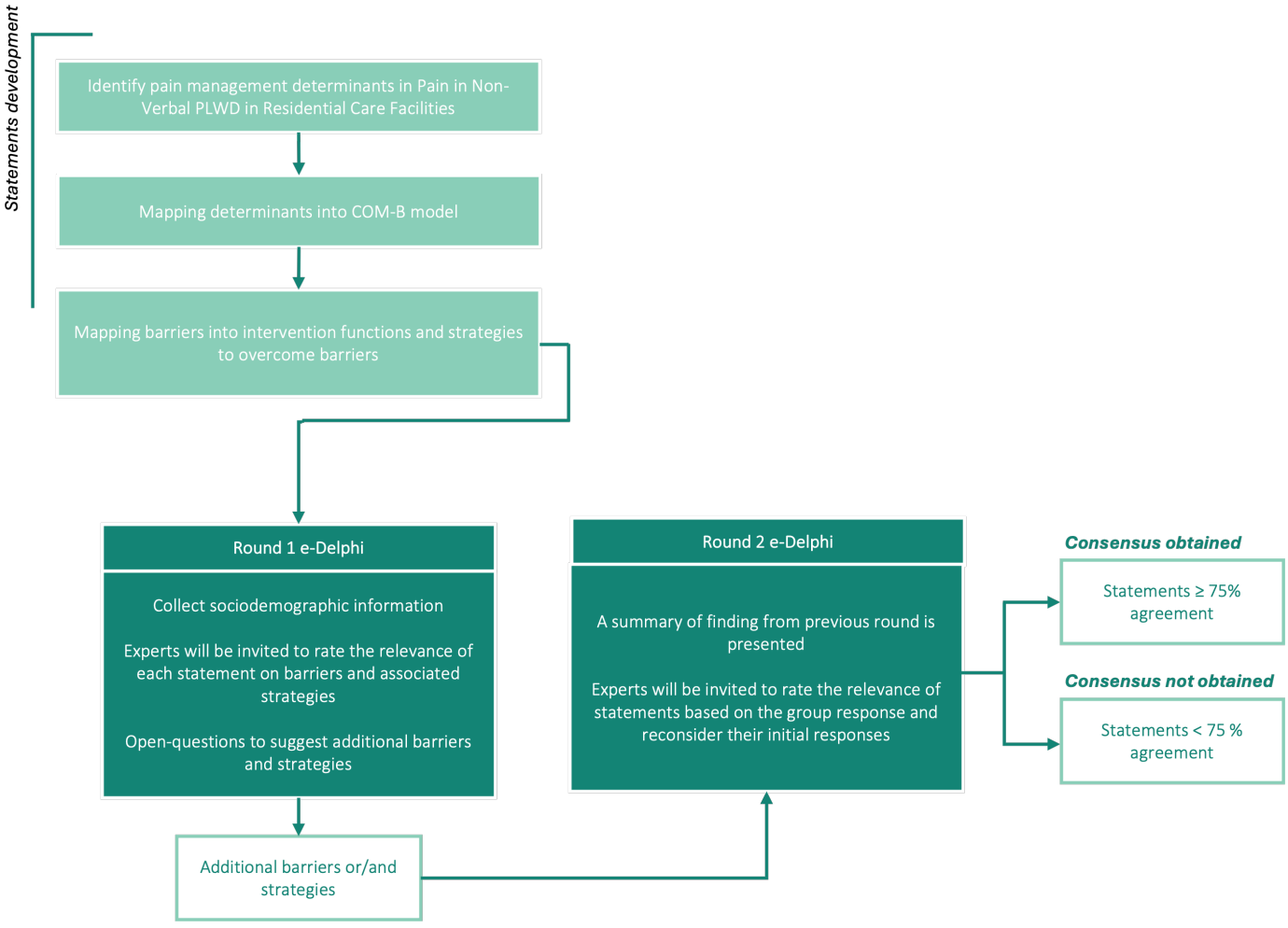

Figure 1 Overview of the planned e-Delphi study. COM-B, capability, opportunity and motivation–behaviour; PLWD, people living with dementia.

were then reviewed by team members to ensure that accuracy and consistency and discrepancies were resolved through discussion. A list of barriers and facilitators per study is provided in the online supplemental material 1.

Repeated determinants across studies were consolidated through consensus. Determinants were then mapped into the COM-B model. Subsequently, the research team reviewed and refined the list of determinants. The results of the mapping exercise are described in table 3. Only the barriers will be included in the e-Delphi statements.

Step 2: mapping determinants into intervention functions and strategies

First, we determined the most appropriate intervention functions to address the selected barriers and influence behavioural change by aligning the individual components of the COM-B behavioural analysis with the linkage matrices provided by the BCW framework.[28] Online supplemental material 2 presents the intervention functions selected.

Second, specific strategies were identified to operationalise each intervention function. These were derived through a combination of sources.

- Literature review of previous interventions of pain management in dementia.[35–41]
- Interdisciplinary team experience and expertise.

This process was initially conducted by one researcher (IBF), who performed the mapping of barriers to intervention functions and proposed preliminary strategies. These initial proposals were subsequently discussed with the interdisciplinary research team, which led to the refinement of existing strategies and the identification of additional ones, ensuring their contextual relevance and practical feasibility.

The result of this step is presented in online supplemental material 3.

Delphi panel composition and expert definition

A heterogeneous panel will be assembled to ensure the inclusion of a wide range of perspectives and to enhance the relevance, acceptability and future applicability of the study findings.[42] The panel will include representatives from key groups potentially impacted by the results. This strategy will also be selected in alignment with the study aim and the need to capture the multifaceted nature

Table 2 Characteristics of the included reviews

Authors (Year)	Title	Aim	Number of included studies	Participants	Setting
May & Scammell (2020)[33]	Nurses' experiences of pain management in end-of-life dementia care: a literature review	To explore nurses' experiences of pain management in end-of-life dementia care	8	Health professionals, mostly nurses and carers	Not mentioned
Jonsdottir and Gunnarsson (2021)[34]	Understanding nurses' knowledge and attitudes towards pain assessment in dementia: a literature review	To identify and explore nurses' knowledge and attitudes towards pain assessment in older people with dementia and how it may affect pain management in this patient group	10	Nurses	Long-term care facilities, hospitals and hospice
Pringle *et al* (2021)[32]	Pain assessment and management in care homes: understanding the context through a scoping review	To explore the complexity of pain recognition, assessment and treatment for residents living in care homes and to understand the contexts that might influence its management	109	Nurses, care assistants, physicians, pharmacists and administrators	Care homes
Smith *et al* (2023)[31]	Pain management for people with dementia: a cross-setting systematic review and metaethnography	To synthesise the qualitative evidence to explore the perspectives of people with dementia, their family, friends, carers and healthcare professionals to pain management	33	Evidence from studies with people with dementia, family members or informal caregivers of people with dementia and formal care workers	Hospital, community setting and residential care facilities
Liao *et al* (2023)[30]	A systematic review of barriers and facilitators of pain management in persons with dementia	To synthesise evidence on the barriers and facilitators of pain management in persons living with dementia	26	Healthcare workers, informal caregivers (families) and multiple roles	Community setting, acute care settings, long-term care setting and hospice settings

Table 3 Pain management barriers and facilitators mapped into COM-B model

COM-B		Facilitators	Barriers
Capability	**Physical capability** is a capability that involves a person's physique and musculoskeletal functioning (eg, balance and dexterity)	Highly trained health workers	Less experienced health workers
		Experienced health workers	
	Psychological capability is a capability that involves a person's mental functioning (eg, understanding and memory)	Highly trained health workers	Lack of familiarity with people living with dementia
		Experienced health workers	Less experienced health workers
		Familiarisation with the patients living with dementia, their preferences, routines and behaviours	Lack of knowledge on pain assessment tools
			Lack of knowledge on pain treatment
			Lack of knowledge on dementia
Motivation	**Reflective motivation** is a motivation that involves conscious thought processes (eg, plans and evaluations)	Patients' comfort and quality of life viewed as a fundamental right	Perceived limitations of assessment tools
			Concerns over medication side effects, adverse events and drug interaction
			Concerns about opioids use
			Concerns about the balance between over and undermedication
			Lack of confidence in pain intervention
			Beliefs and perceptions of care home staff (eg, pain as a normal aspect of ageing)
			Different wishes, goals and attitudes towards treatments among healthcare workers were related to delayed pain treatment
			Lack of proactive pain assessment
	Automatic motivation is a motivation that involves habitual, instinctive, drive-related and affective processes (eg, desires and habits)		Prioritisation of antipsychotic medication over pain medication

Continued

Table 3 Continued

COM-B		Facilitators	Barriers
Opportunity	**Physical opportunity** is a opportunity that involves inanimate parts of the environmental system and time (eg, financial and material resources)	Availability of training programmes	Lack of available training
		Adequate staffing levels	Distance of training location
		Available pain management guidelines	Lack of financial support for training
		Use of non-pharmacological interventions	Limited training among health workers
			Health workers time constraints
			Heavy workloads
			Poor staffing levels
			Type of working contract (eg, part-time or short-term contracts)
			Staff turnover
			Poor reimbursement for providers' time
			Lack of guidelines on pain assessment
			Lack of guidelines on pain treatment
			Lack of accessibility of pain assessment tools for PLWD
			Complexity and reliability of pain assessment tools
			Limited accessibility, cost and lack of evidence on non-pharmacological intervention in people with dementia
			Lack of pain documentation and report
	Social opportunity is a opportunity that involves other people and organisations (eg, culture and social norms)	Family support	BPSDs
		Clear communication channels between care providers and familiarity	Communication difficulties of people with dementia
		Obtain patient information from primary caregivers	Cognitive and functional impairments
		Good collaboration between healthcare workers and informal caregivers (ie, family)	Lack of continuity of care
		Pain management as a leadership priority	Lack of interdisciplinary support and communication barriers among health workers
		Observe BPSD and pain-related behaviours	Negative relationship and communication among health workers and informal caregivers
		Positive relationships within the healthcare team	
		Use multiple and effective communication strategies	
		Continuous care and collaboration among shifts, units and settings	

BPSDs, behaviour and psychological symptoms of dementia; COM-B, capability, opportunity and motivation–behaviour; PLWD, people living with dementia.

Table 4 Operational definitions of experts

Group	Expert definition
Physicians	► At least 3 years of work experience in the residential care facility setting ► Holding a competence in pain medicine or a specialisation in any of these areas. General practice Internal medicine Physical and rehabilitation medicine Neurology Psychiatry Alternatively, should recruitment according to the above two criteria prove unfeasible, experts meeting any of these criteria may be included, provided that the overall composition of this professional group ensures a balanced representation.
Nurses	► At least 3 years of work experience in the residential care facility setting ► Holding a specialisation in any of these areas. Family health nursing Rehabilitation nursing Medical-surgical nursing—chronic condition Medical-surgical nursing—palliative situation Mental health and psychiatric nursing Alternatively, should recruitment according to the above two criteria prove unfeasible, experts meeting any of these criteria may be included, provided that the overall composition of this professional group ensures a balanced representation.
Physiotherapists	► At least 3 years of work experience in the residential care facility setting ► Holding a master or PhD degree in physiotherapy or related clinical areas (eg, musculoskeletal or neurological diseases) Alternatively, should recruitment according to the above two criteria prove unfeasible, experts meeting any of these criteria may be included, provided that the overall composition of this professional group ensures a balanced representation.
Psychologists	► At least 3 years of work experience in the residential care facility setting ► Holding a specialisation in clinical and health psychology or master's in clinical psychology and/or health psychology or training in pain management (master, PhD or shorter course) Alternatively, should recruitment according to the above two criteria prove unfeasible, experts meeting any of these criteria may be included, provided that the overall composition of this professional group ensures a balanced representation.
Nurse assistants	► At least 3 years of work experience in the residential care facility setting ► Training in gerontology or another relevant area (eg, 2-year Higher Professional Technical Programmes or shorter certified courses)
Managers of residential care facilities	► At least 3 years of work experience as a manager in the residential care facility setting
Policymakers	► Currently engaged in decision-making at a policy level relevant to pain management

of pain management in non-verbal people living with dementia within Portuguese residential care settings.

For the purpose of this study, an individual will be considered an expert if they have experience in caring for non-verbal people living with dementia in residential care facilities in Portugal coupled with professional credentials or status (eg, policymakers and managers of residential care facilities). The definition for an expert in each professional group was formulated considering the national context (table 4).

Delphi panel size and recruitment

Empirical evidence indicates that a sample size of 60–80 participants yields a high level of replicability in results when involving multiple stakeholder groups.[43] Assuming an attrition rate of 20% based on prior experience and optimised recruitment strategies, the recruitment of a minimum of 72 experts is envisaged.

We will employ purposive sampling as the primary sampling technique based on the operational definition of experts. First, residential care facilities across Portugal will be identified and contacted based on a publicly available roster to facilitate the identification of eligible experts. Second, we will identify national experts through relevant publications in the field and existing professional networks. Third, we will engage with organisations, such as the Portuguese Pain Association (APED), Alzheimer Portugal and professional regulatory bodies, to facilitate the identification of suitable experts and to disseminate information about the study. Fourth, we will promote the

e-Delphi study through social media channels, leveraging both researchers' and institutional networks.

Snowball sampling will also be used as a secondary sampling technique. Experts will be asked to nominate potentially eligible colleagues with confirmed interest in participating, who will be invited to contact the research team to discuss participation.

Drawing on the literature on effective recruitment,[22 42] we will also employ the following strategies.

- Personalised email invitation will be sent to participants, accompanied by an infographic highlighting the key aspects of the study (online supplemental material 4), a detailed information leaflet and contact details of the lead researcher (IBF) (online supplemental material 5).
- A short video will be created explaining the e-Delphi study and what participation involves, to be shared by email and social media.
- Ask professional regulatory bodies and other relevant organisations to disseminate the study via newsletters, institutional bulletins or social media networks.

Eligibility will be verified by the lead researcher on receipt of the expert's expression of interest, and participants will provide written informed consent.

Data collection instrument and procedures

Questionnaires in the two rounds will be deployed via Qualtrics software. Data collection is expected to start in August 2025 and is expected to be completed within a 4-month period.

The first round of the survey will include two sections (online supplemental material 6). In the first section, demographic and background data will be collected, such as work experience and work experience in residential care facilities. In the second section, experts will be invited to rate the relevance of barriers and strategies for pain management in non-verbal people living with dementia. Relevance is defined as the value and appropriateness of barrier and strategy. A five-point Likert scale will be used:

1. not relevant at all
2. slightly relevant
3. neither irrelevant nor relevant
4. relevant
5. very relevant.

To enhance data validity, an additional response option—*Not applicable to my role*—will be provided. This intends to accommodate the responses of participants for whom the item may not align with their professional responsibilities. For example, in Portugal, nurse assistants are not responsible for administering medication without supervision of a nurse.

Each statement on barriers and the strategy(ies) will be accompanied by a comment box, allowing participants to optionally provide clarifications for their responses, propose revisions and/or suggest any additional barriers and strategies they believe should be considered for inclusion.

The initial survey will be piloted using a convenience sample of 2–3 academics and healthcare professionals to check the questionnaire's face validity and the user experience with the software.

The questionnaires will be completed quasi-anonymously, where participants remain anonymous to one another, but can be identified by one member of the research team (IBF) via coded identifiers. Participants will have up to 3 weeks to submit their responses for each e-Delphi round.

For the second round, participants will receive a summarised report of rating frequencies in Round 1, their own rating for each statement and comments to allow them to reflect on the group response and potentially reconsider their initial ratings. Newly proposed statements will be incorporated in the questionnaire and subjected to rating.

We will use a multimodal approach to enhance participant retention throughout the Delphi process by[22]:

- sending regular email updates to keep participants informed about study progress;
- enabling the option to save and return to the questionnaire and including a progress bar to help participants track their completion;
- sending personalised reminder emails during each round to encourage timely responses while also allowing flexibility in deadlines to accommodate participants' needs;
- presenting visual feedback in each round, including graphs and summaries of individual and group responses;
- ensuring quick and responsive email support to address any questions or technical issues;
- providing incentives via a prize draw, offering 30 vouchers worth €20 each;
- offering a thank-you message and a certificate of completion at the end of data collection;
- sharing a final summary report with participants in an accessible and user-friendly format;
- offering the option of public recognition as an expert contributor for participants who wish to be acknowledged.

Consensus definition

To define consensus, we will use the percent agreement approach. There is no universally accepted threshold for defining consensus in Delphi studies. As noted by Niederberger and Spranger,[44] thresholds in health-related Delphi research often start at 60%, though values vary across studies. Similarly, Diamond *et al*[45] found a median consensus threshold of 75% in their literature review, highlighting methodological heterogeneity. Shang[46] further supports this stating that a level between 70% and 80% agreement is most adopted and considered rigorous. Based on this evidence, we define the consensus when ≥75% of participants rate a statement.

Data management and analysis

Each participant will be assigned a unique alphanumeric code to enable data integration while preserving pseudoanonymity. All study data will be stored on password-protected systems. To minimise reidentification risk, the mapping between participant identities and their corresponding codes will be maintained by a single researcher (IBF), stored separately from the primary dataset.

Data generated from the round will be extracted and descriptive analysis will be performed via Qualtrics software with the aid of Statistical Package for Social Sciences (IBM SPSS Statistics). For each round, the analysis will include the calculation of the frequency distributions for each statement. A statement will be considered to have reached consensus 'in' if ≥75% of participants rate it as 'relevant' or 'very relevant' (scores 4 or 5), or consensus 'out' if ≥75% rate it as 'not relevant at all' or 'slightly relevant' (scores 1 or 2). Responses marked as *Not applicable for my role* will be excluded from the consensus calculation.

Textual comments provided by participants will be analysed thematically with responses at the statement level. In cases of divergent interpretations, a third team member will be involved to resolve discrepancies through discussion. Similar suggestions for amendments from two or more experts will be carried out for the statement definition.

Patient and public involvement

None.

ETHICS AND DISSEMINATION

Ethical approval for this study was obtained from the Egas Moniz Ethics Committee (Ref. 1586), and all procedures will comply with the Declaration of Helsinki.[47] Informed consent will be obtained from all participants. Any amendments to the protocol will be submitted to the Egas Moniz Ethics Committee and described in future study reports.

The findings will be disseminated through a peer-reviewed publication, scientific events and stakeholder networks, including residential care facilities, to inform future practice and policy in dementia care.

DISCUSSION

This e-Delphi protocol outlines a structured and theory-informed approach to establishing consensus on barriers and strategies for pain management in non-verbal people living with dementia in Portuguese residential care facilities. By applying the BCW framework, this study ensures that barriers are systematically linked to intervention functions and strategies, thereby enhancing the theoretical robustness and practical relevance of the findings.

The findings of this study are expected to have implications for research and health policy. From a research perspective, they will contribute to the knowledge on relevant barriers and strategies for pain management in dementia in a national context. The consensus achieved will provide a foundation for the development of an intervention aimed at improving pain management in non-verbal people with dementia. This approach is consistent with the Medical Research Council's framework for the development and evaluation of complex interventions, which underscores the need for a theoretical and empirical foundation before designing and testing interventions.[48]

Similar approaches have been employed in the development of complex interventions in dementia. For example, Walsh *et al*[49] described the systematic development of an intervention to address inappropriate antipsychotic prescribing in nursing home residents with dementia. The intervention development was informed by the BCW framework, which facilitated the selection of behaviour change techniques by linking the behavioural determinants to potential intervention functions.[49 50] While their work focused on medication optimisation, the present study extends the body of knowledge to a different area in dementia care, applying a similarly theory-driven methodology.

Lun *et al*[51] conducted a modified Delphi study to establish consensus on barriers to appropriate prescribing for older adults with multimorbidity. These barriers were subsequently mapped to intervention functions to inform future intervention development. However, the expert panel was not involved in identifying the intervention functions, which may limit their contextual relevance and practical applicability. In contrast, our study will reach consensus on both barriers and corresponding strategies, thereby potentially enhancing the acceptability and contextual alignment of a future intervention.

The Delphi results are expected to lead to recommendations for improving pain management in non-verbal people with dementia in residential care facilities, which could inform health policy on pain management in this population.

In Portugal, the existing guidelines for the assessment and treatment of pain in older adults with chronic pain remain general and offer limited recommendations for people with dementia. For example, they emphasise the importance of observing behaviour when communication difficulties are present but provide little practical guidance on how assessment should be conducted or which tools should be used.[52] Furthermore, this study goes beyond clinical recommendations by identifying organisational factors that may be critical to improving dementia care. The National Strategic Plan for the Prevention and Control of Pain highlights the need to develop training recommendations.[53] The findings from our study can inform the prioritisation of training areas in the context of dementia.

Another strength of the study is its rigour, ensured by adherence to the ACCORD reporting guidelines, the publication of the study protocol and an effort to use current empirical research to underpin methodological decisions. The publication of the study protocol ensures transparency and strengthens the integrity of the research

process. For example, Grant *et al*[54] reanalysed data from eight Delphi panels, applying 25 different commonly used analysis methods to the same dataset. This approach resulted in varying outcomes, with consensus rates ranging from 0% to 84%. The authors expressed a legitimate concern that, due to the arbitrary definition of consensus in Delphi panels, researchers may exploit undisclosed data collection and analysis procedures to apply post hoc methods and selectively present the most favourable results. They also observed that, although typically Delphi studies in health research include the definitions of consensus when publishing results, it is still uncommon to preregister studies or publish protocols that specify how consensus will be determined prior to data collection and analysis. We agree with Grant *et al*'s plea for greater transparency in Delphi studies and have submitted this protocol in accordance with their recommendations on the minimum set of items to include in preanalysis plans. Simultaneously, this protocol also addresses the criticism of insufficient detail in the procedures employed raised by Niederberger and Spranger.[44]

For estimating the size of a heterogeneous panel, we drew on the work of Manyara *et al*[43], rather than relying on commonly used, yet often inconsistent, samples in previous Delphi panels. There is no definitive guidance on sample size estimation and an overview of systematic reviews on Delphi panels for consensus highlights considerable variability in panel size, ranging from 3 to 731 (mean=40).[44]

Several studies have explored approaches to maximise retention in Delphi panels, yielding insights into both incentive and non-incentive strategies. A consistent finding is that thoughtful design and communication can reduce attrition. For example, Hall *et al*[22] conducted a three-round international e-Delphi for core outcome development in tinnitus (the COMiT'ID study) and tracked recruitment and retention outcomes in an international sample. They achieved high completion rates across all three rounds of their 66-item questionnaire, with 76%–91% of participants from each stakeholder group completing every round.[22] The study involved 719 professionals and healthcare users. Over 350 participants also provided feedback about the Delphi process, confirming that they were generally satisfied with the methods used to keep them engaged.[22]

Another illustrative case is a Delphi study conducted in the Netherlands to establish national standards for emergency departments; the study engaged 20 experts to evaluate and refine 55 items across 8 iterative rounds, followed by an additional confirmation round—an unusually long Delphi process, which achieved a 100% response rate across all rounds.[55] To support engagement throughout, the researchers implemented multimodal strategies. The survey design featured a clear and consistent presentation of items, although without piloting, and each round began with items that had not yet reached consensus. The study applied explicit rules for item adjustment, whereby any item receiving similar revision suggestions from at least two panellists was modified and resubmitted in the following round. Communication was two-channel, with survey links sent via email and a corresponding text message alert. Additionally, reminders were personalised based on each panellist's prior response behaviour and contextual factors, such as national holidays. Another factor that likely contributed to the study's remarkable 100% retention rate was the initial invitation: phone calls made by a well-regarded clinical leader to peers. Although this is not easily replicated by all research teams, it does flag up the potential value of personalised telephone contact where appropriate.

Incentives have been explored as a strategy to improve survey participation rates. Although evidence of their effectiveness in Delphi studies is limited, insights from survey research may reasonably be applied due to methodological similarities between the two approaches. Abdelazeem *et al*[56] conducted a meta-analysis of 46 randomised controlled trials involving over 100 000 participants to evaluate the impact of different incentive types on response rates. The results showed that incentives increased participation compared with no incentive, with direct monetary payments being more effective than vouchers or lotteries.

The choice of rating scales in Delphi studies is variable. Niederberger and Spranger[44] note that both five-point and nine-point Likert-type scales are among the most frequently used formats in health-related Delphi research. However, selecting the appropriate scale requires consideration of its potential impacts. A study investigating the influence of different design characteristics on response rates in Delphi studies found a significant association between the number of scale points and response rates.[57] Specifically, studies employing scales with more response options (eg, nine-point scales) experienced lower participant retention between rounds compared with those using fewer options. The authors concluded that longer or more complex rating scales might impose a greater cognitive burden on participants, potentially leading to increased attrition.[57]

A significant limitation of the Delphi is the lack of standardised procedures for key methodological aspects, such as sample size and the definition of consensus. As detailed above, we sought to address this by drawing on what we considered to be the best available evidence. Another limitation is that recruitment will not be based on random sampling, making it prone to selection bias and potentially unrepresentative of all stakeholder perspectives. Finally, consensus should be interpreted as a structured synthesis of expert opinions rather than a definitive conclusion. Empirical studies are needed to examine the real-world relevance and effectiveness of strategies related to pain management in people with dementia, which will be addressed in the e-cuidaDOR2 project.

Within e-cuidaDOR2, we will develop a theory and evidence-based intervention to improve pain management in non-verbal people with dementia, drawing on the e-Delphi findings. The intervention will target formal

caregivers, who will be involved in a cocreation process to ensure alignment with their needs and preferences. In addition to these stakeholders, it will be important to integrate physicians with formally recognised geriatrics competence, despite their scarcity in Portugal. Future research in the national context should also consider the forthcoming gerontogeriatric nursing specialty, currently under development, to ensure the incorporation of geriatric nursing perspectives.

Contributors IBF and MG were responsible for securing funding for the project. The conceptualisation of the study was developed collaboratively by IBF, MG, JDH and KH. Methodological design was undertaken by IBF and MG. IBF was responsible for the literature review and for listing all identified barriers and facilitators. All team members reviewed the barriers and facilitators, intervention functions and selected strategies. IBF and CR were responsible for developing the data collection instrument, which was subsequently reviewed by MG. IBF and MG were primarily responsible for drafting the original manuscript. All authors—CR, RG, JDH, KH and TA—contributed to the critical review and editing of the manuscript and approved the final version. IBF is the guarantor.

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Competing interests JDH and KH are shareholders in PainChek Ltd (formerly known as EPAT Technologies Ltd.), which is commercialising the PainChek App. They are also named as coinventors with Mustafa Atee on the patent entitled 'A pain assessment method and system' (patent granted in the USA, Europe, China and Japan). JDH is employed as the Chief Scientific Officer of PainChek Ltd. and holds an Emeritus Professor appointment at the Curtin Medical School, Curtin University. KH is employed as an independent consultant by PainChek Ltd. in the role of Senior Research Scientist and he is a Professor at the University of Prishtina. The remaining authors declared no potential conflicts of interest with respect to the research, authorship and publication of this article.

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