This article has been accepted for publication in MH following peer review.
The definitive copyedited, typeset version is available online at 10.1136/medhum-2023-012718

# An Alternative Theoretical Approach to Develop a New Conception about Pain in People with Dementia

## Abstract

The theoretical approach presented in this paper describes a novel experimental-theoretical methodology to conceptualise pain in people with dementia. Existing procedures for assessment of pain rely on subjective self-report using pain questionnaires and rating scales that have proven to be highly problematic where a person has dementia. Consequently, pain in people with dementia can be undetected and/or undertreated. To address that, we have developed an alternative experimental approach that builds on theoretical and methodological precedents from the arts, humanities and social sciences, for instance, Visual Thinking Strategies, Creative Thinking or Two-Step Flow of Communication. Based on this approach, we designed an experimental workshop setting to ingrate these methodologies to explore pain and its expression in people with dementia. This had led to a new definition of pain as an interruption of the socially mediated process of bodily meaning-making. Furthermore, our experimental methodology could equally well be applied as a training method, where professional staff can intervene into existing implicit meanings and understandings of medical issues. These results emphasise that the future of pain research need to need to consider the relational aspects of pain more seriously.

Keywords: Pain, Dementia, Visual Thinking Strategies, Meaning-making, Communication

# Introduction: pain recognition in people with dementia

This paper describes a novel experimental-theoretical methodology to provide a better conceptualisation about pain in people with dementia. There are over 50 million people in the world with dementia with the numbers expected almost to double in the next twenty years (Alzheimer's Disease International, 2021). Understanding and treating pain is a common problem among this large and growing population.

Physical and mental pain are among the most common symptoms experienced by people with dementia (Scherder et al., 2009; Lautenbacher & Gibson, 2016). The majority of people living with dementia have at least three comorbid conditions (Scrutton & Brancati 2016; Timmons et al. 2016), which commonly include chronic obstructive pulmonary disease, cardiovascular disease, hypertension, diabetes, sensory impairment, and musculoskeletal disorders (Browne et al. 2017; Bunn et al., 2016). Many of these co-morbid conditions can induce pain, but no existing medical procedure, e.g., measuring electric signals in the nervous system, muscle contraction or electrical heatmaps of the brain, can objectively diagnose that pain. Detecting and responding to pain experienced by people with dementia is an important clinical issue, as pain may cause worsening of the person's condition (Scherder et al., 2009), e.g., increased cognitive impairment or changes in behaviour. As already stressed by Loeser (1991), an important issue is the paucity of medical theory in conceptualising pain, which is often ineffective, but may be even one of the causes of this rapidly growing problem of pain diagnoses and management.

## Clinical definitions of pain

> "An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage." International Association for the Study of Pain (cited in Merkel et al. 1979)

> "An unpleasant emotional experience usually initiated by noxious stimulus and transmitted over a specialized neural network to the central nervous system where it is interpreted as such." Bennett (1984)

> "Pain is an unpleasant sensation localized to a part of the body." (Rathmell & Fields 2013)

> "Pain is a mutually recognizable somatic experience that reflects a person's apprehension of threat to their bodily or existential integrity." Cohen et al. (2018)

> "An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" Revised Definition of International Association for the Study of Pain (Raja et al. 2020)

These common clinical definitions of pain tend to conceptualise pain mainly as bodily experience, and variously describe it, for example, as a sensation or a somatic experience that is negative in nature[i]. These definitions of pain restrict the meaning of pain to neurophysiological activities, e.g., as a somatic experience and neglect to consider the meaning of pain for a person, which requires a more sociological approach to pain (see Bendelow & Williams 1995).[ii] This is perhaps unsurprising, when we shift the focus to their conceptualisation. Medical theories are typically challenged for their practical application (see Alderson 1998; Thagard 2005), but very little is known about the practice of theorisation in medicine.

The few studies that exist in this area suggest that medical definitions or theories emerge from "intuitive heuristics performed by individual professionals." (Malterud 1993, 81); "reviews of reviews" (Smith et al. 2012; see also Gates et al. 2022) or summarising and reorganising existing text-book definitions (Hucklenbroich 2017). Based on these existing practices of theorisation in medicine we can understand why the above-mentioned definitions are very consistent, but also very similar to each other. This is because they more or less derive from tautological processes that strongly build on each other. As stated by Corns (2020), there is a need for complexity and to reject an orthodoxy of simplistic conceptualisations. For instance, Williams and Craig (2016) emphasised that only such a more complex definition can account for a wider range of sensory, emotional, cognitive and social factors that influence the experience of pain. The aim of this paper with be double-fold: (1) to intervene into this implicit process of theorisation in medicine to develop a new approach that will assist medical professionals in the creation of new medical concepts and (2) to develop a new definition of pain, which is able to integrate its communicative and social dimensions, that is, being able to talk about it, and the importance of where and when the pain is being experienced.

## Diagnosing Pain: From Questionnaires to Interaction

Existing procedures of assessing pain that build on these clinical definitions rely on pain questionnaires and rating scales, which employ large and disparate vocabularies to describe and categorise pain, ranging from 100 words to 200 in various languages (see Breivik et al., 2008; Mathieson et al. 2015; De Silva et al. 2020). However, a growing body of research suggests that these tools are highly problematic, not just for people with dementia (see Herr et al., 2017). Pain ratings give an illusion suggesting that pain can be assessed in an objective way, which reflects the abovementioned clinical definitions. However, this ignores that pain ratings are part of a sequence of complex sociological interactions to establish the significance of the pain, which include a variety of subjective interpreters that include the patient, carer, nurse, pharmacists or GP (Heath, 1989; Jenkins, 2015). Consequently, pain scale ratings by the same person have proved inconsistent and unreliable from one day to the next. Relying on complex vocabularies that are not part of people's active language competence is also a problem, as there is significant ambiguity about the meaning of words in the context of a given assessment (Herr, 2011; Schofield, 2018). Ehrlich (1985, p. 177) therefore concluded in his research on the language of pain: ‘Speaking about pain is thus one of the most difficult forms of linguistic activities’.

Consequently, pain in people with dementia can be undetected and/or undertreated (Achterberg et al. 2019, Harrison Dening, 2020, Liao et al. 2023). This may lead to under-treatment with analgesics or inappropriate treatment, e.g., antipsychotics for agitated behaviour (Brunkert et al., 2019). In some older, but still relevant research, relatives and carers were asked about how pain was managed in the person they cared for. Many reported that the person experienced significant pain but that its recognition, and thus control, was often poor (McCarthy et al., 1997). Other research has found differences in the experience of trauma, such as hip fracture, where people with dementia were prescribed only a third as much pain relief as those people without dementia (Morrison & Siu, 2000; Armour & Murphy-Jones, 2016).

As mentioned above, our more sociological approach to pain argues that pain diagnosis depends on interactive co-construction and disparate complex vocabularies, particular challenges arise in relation to people with dementia (Harrison Dening 2020). More specifically, dementia leads to decline in linguistic skills (e.g., expressing, interpreting and understanding meanings in oral and written form), and the ability to engage interactively in negotiating and identifying pain is severely challenged. As people with dementia have difficulty in communicating their pain, care staff may fail to understand pain-related behaviours and thus misinterpret pain signals (Oosterman et al, 2014). However, little has been done to address the challenges of understanding pain in people with dementia. As a step towards bridging this gap, the experimental approach proposed here builds on theoretical and methodological precedents from the arts, humanities and social sciences to unravel the complex processes of expressing and interpreting meaning.

Scholars in several disciplines have noted that meaning-making is a complex, creative, collaborative and selective process beyond the mere transmission of information from one person to another (MacKay, 1960; Alexander, 2003; Morgner, 2022). For instance, an everyday conversation between two close friends differs significantly from more formal interactions (e.g., in a courtroom or between doctor and patient) in terms of both the challenges and freedoms of managing and negotiating meaning. Communication about pain is complex, as it is a sensitive topic with a limited lexicon, and is further complicated in people with dementia as communication has to rely more on non-verbal modes of expression. Consequently, our research was designed to address the limitations of current clinical definitions by developing a conceptual methodology that could lead to new ways to gain a better understanding of pain in people with dementia.

In order to overcome the limitations of current clinical definitions of pain and to devise new ways to assess pain, this research built on recent debates about the importance of involving people with dementia in research more generally, and sought to devise an accessible methodology that overcomes some of the existing issues identified in current research (see Sheth 2019, (Wilkinson & Weitkamp, 2020).

In recent research, several studies (Popay & Williams, 1996; Caron-Flinterman et al., 2005; Duffett, 2017) have noted obstacles to participation created by the uneven distribution of knowledge. Some forms of knowledge are valued as having greater relevance and so require less justification, in turn rendering other forms of knowledge more peripheral. These asymmetries make it easier for those in possession of recognized knowledge to be included in the debate while effectively silencing others. Other research highlights the role of power in facilitating, constraining or preventing social action (Kelleher et al., 1994; Kerr et al., 2007; Boardman, 2014). In medical and other institutional contexts, authority is typically perceived as a legitimate form of power, and those in authority can enable or prevent the participation of others. Claims of authority are difficult to challenge because they reflect institutional norms, so creating a conversational structure that favours those in authority.

Existing research also highlights the need to take account of variations in verbal communication and debating skills (Jordan et al., 2020; Elberse et al., 2011). In particular, while professionals are more likely to have experience of public speaking or discussing issues with other professionals, lay people and people with dementia may feel less confident in voicing their opinions. A second communication issue mentioned in the literature is that dementia may hinder the ability to follow a fast-paced or complex debate that uses academic or professional jargon requiring a higher level of health literacy. This again relates to the role of power in designating the roles of speaker and listener, as varying conversation skills can determine participants' ability to participate or share their meaning. In enabling innovative solutions to pain diagnosis in people with dementia, it is also important not to limit the discussion by predetermining the subject matter. Equally, the literature confirms the importance of avoiding unduly open discussion that makes it more difficult to identify and select appropriate innovations (Morrison & Dearden, 2013).

Finally, active and creative participation depends on a welcoming, stimulating and non-stigmatising atmosphere. When we refer to the term creative in the context of this workshop, we do not refer to creative activities, such as drawing or singing, but to creative thinking. With creative thinking we refer to the ability to consider something in a new way, encompassing the generation of new ideas or concepts, or finding fresh associations between existing ideas or concepts. This involves divergent thinking, which seeks multiple solutions to a problem rather than focusing on a single answer. This kind of thinking is characterised by its flexibility, originality, and the willingness to explore unconventional solutions (see Mumford et al. 2013) There is evidence that individuals will avoid participation if labelled as people with dementia (Bond & Lynne, 2001; Garand et al., 2009; Manafo et al., 2018), as they may feel that this reduces their social standing to this single identifier. Based on this review of the literature, we devised an experimental-theoretical workshop that combined methodologies from performing arts, arts education and communication studies to enable a meaningful contribution by people with dementia.

# Methodological approach

## An experimental-theoretical workshop

To plan the conduct of the workshop and manage the issues of equality, power and knowledge, we devised a conversational sociological interactive framework for interpreting the meaning of pain. The central idea of this interactive meaning-making was broadly envisaged in the form of a *workshop*, with 'workshop' taken from performing arts contexts. In this context, a workshop format combines focused group discussions with an openness to improvisation and testing of new ideas as a research method to explore new understandings and meanings before formalising any outcomes (Tarr et al., 2017). We aimed to avoid limiting conceptual constructions to a predefined clinical context and also reflected on the sociological importance of meaning-making with respect to pain, in opposition to an isolationist arm-chair construction. Additionally, this workshop discussion format makes no distinction between those who enable actions and those who respond. In other words, we did not group participants into 'authorities' (academics, professionals) and others, as might happen in a traditional lecture hall. On the same basis, authority to speak was not pre-delegated or unilateral; following Goffman (1981), the traditional roles of (authorised) speaker and listener were disrupted enabling all to speak or to listen as they wished, and to improvise and think beyond any authorised roles. To that end, participants were arranged in a circle, with no overall authority, mirroring the collaborative communication models of deliberative democracy and so-called round-table talks (Perkins, 2003; Reykowski, 2019).

While this set-up avoids any sense of hierarchy, it does not automatically ensure that workshop participation and contribution will be balanced. In particular, this face-to-face discussion format can impose significant pressure on participants because it becomes virtually impossible *not* to communicate (Beavin et al., 1967). Consequently, participants feel obliged to produce ideas quickly, and there is a risk that they may detach from the discussion to reflect and prepare their comments. As this undermines listening, contributions may display an erratic quality rather than building on each other (Martin et al., 2012; Muijs & Reynolds, 2017). Clearly, this erratic approach must be avoided in order to deliver tangible results in terms of learning and innovation. Because detached opinions also tend to be presented quite rapidly (Hawkins, 1985; Savoy & Yunyongying, 2013), this poses particular challenges for anyone who is unused to fast-paced discussion, including people with dementia. To mitigate these issues and to enable all participants to contribute in a meaningful way, we incorporated two further elements: *paraphrasing* as used in Visual Thinking Strategies (VTS) and a *two-step communication flow*.

## Paraphrasing

Paraphrasing forms part of the Visual Thinking Strategies (VTS) approach developed at the New York Museum of Modern Art (MoMA) in the 1990s (Housen, 2001–2002). Developed in an arts education context, this format was designed to improve visitors' learning experience during guided tours of the museum. The approach was informed by evidence that, when discussing works of art, participants were unable to listen to or follow others' comments because of the complexity of formulating their own response when the subsequent communication slot opened. As a result, visitors were unable to collaborate or complement each other to deepen their interpretation of the artworks. To overcome this issue, VTS introduced the key tool of advanced paraphrasing. Paraphrasing is defined as neutral or factual rephrasing by the facilitator of what the previous speaker has just said. The facilitator acts as a mirror that buys time, so that the participants can gain clarity on their own thinking. This crucial intervention slows communication and eases any anxiety about lack of preparation by repeating what others have to say in summary form before inviting subsequent statements. In this way, statements can build on what has already been said, facilitating more complex communication through open exploration of different ideas. By implication, the role of the 'authorised' speaker is also disrupted, as those assigned to provide answers are equally enabled to listen.

## Two-step communication flow

While VTS can in principle deal with the challenges around pace and meaningful contribution, those with more experience of discussion nevertheless remain in a privileged position in terms of attributes such as eloquence or confidence. To build the confidence of less experienced participants, our experimental-theoretical methodology also incorporated two-step communication flow as first proposed by Katz and Lazarsfeld (1955) in the context of mass communication studies. They wanted to understand how arguments presented in the media are received by the audience when relayed through intermediaries. They discovered that intermediaries play a risk-taking role as pioneers, showcasing different models before formulating an opinion. This has a shielding effect, as their ideas can be adopted and re-utilised by others to enhance their communication skills. However, it should also be noted that providing an example through the first group discussion needs to be carefully managed, so that it does not limit the creative thinking. We emphasised the experimental nature of this discussion to account for this risk.

On that basis, the workshop was divided into two distinct phases. The first phase was confined to speakers with more experience of debating as an inner circle surrounded by the others in an arrangement modelled on televised political debates (Livingstone & Lunt, 1994). Those in the outer circle were informed that, in a second step, the inner round table debate would be extended to everyone, using the same paraphrasing approach. In this way, the outer circle was able to gain a sense of the content, as well as how such issues are debated and how arguments are presented. That way all participants were equipped with a number of strategies to experiment with for their own purposes.

In summary, participants were helped to overcome any obstacles to exploring new ways of understanding pain in people with dementia by means of a novel experimental approach. This combined arts-based research methods like workshops and VTS with theoretical inputs from the field of communication studies, including round-table talks and two-step communication flow and resulted in a half-day workshop for a diverse group of stakeholders to explore the understanding of pain in dementia.

Specifically, the study explored two main research questions:

1. What new understandings about pain in dementia emerged from the workshop?
2. Is this an appropriate, accessible and effective methodology for exploring such topics?

## Methods

### Participants

Based on the considerations discussed above, the workshop participants were recruited in two stages. The first stage was to recruit a group of speakers to introduce the topic to the workshop. Invited speakers (N=8) were drawn from several relevant professional backgrounds, including nursing, therapy and research, and included four pain nurses from a local private hospice, a care home and a National Health Service (NHS) Trust; two art therapists who treated pain; a psychologist; and an academic researcher from the field of communication studies. The group of speakers was gender balanced (N=4/4) and included people (N=2) from black and minority ethnic groups. The aim was to avoid any one-sided preference for certain medical practices, and so to reveal any gaps, differences or conflicting approaches.

The second stage was an open call that invited people with a general interest in this topic to participate. The workshop promotional material reflected our intention for an open, collaborative approach to exploring a topic of high general relevance. Considerable effort was made to promote the workshop to a diverse audience through local dementia networks, Alzheimer's Research UK East Midlands and personal contacts. The workshop attracted a wider circle of 22 additional participants which represented a diverse group in terms of gender, ethnicity and educational background, including people with dementia and their carers (N=10), general as well as specialist nurses and allied health professionals (N=5), GPs (N=2), academics (N=3), and people working in hospital management (N=2).

### Location

To address issues of equality, power and labelling, we devoted significant consideration to the location of the workshop and the supporting environment. For instance, care was taken to avoid any context that would reinforce the authority of any particular profession, such as a university building, care home or arts space. Instead, we sought to identify a space with a friendly and non-hierarchical atmosphere, and conviviality research directed our attention to pubs and restaurants as appropriate settings (see the classic study by Synder, 1967). It was equally important to select a space with acoustics that would support conversation and a relaxed 'workshop' atmosphere. We ruled out office spaces as somewhat sterile, potentially hindering creative thought. Finally, we needed a space that would be accessible and safe for people with dementia. Taking account of all these factors, we identified a function room at the Trent Bridge cricket ground as a suitable venue for the workshop. The room combined a relaxed social setting of a pub or bar with large windows overlooking the cricket field and an open workplace atmosphere. As the room has also been used by another dementia group, stadium staff had received appropriate training and were able to guide participants on the day.

The stadium is also just a few minutes from the main rail station, with good public transport connections and easy-access parking.

## Procedure

All participants were offered tea, coffee and biscuits, both on arrival and ad lib throughout the workshop. An adjacent hospitality room was available to anyone who needed a rest or a time-out. Finally, all participants received name tags to ensure that everybody felt included and on an equal footing with others (on the process, see Figure 1).

**Figure 1 about here**

Figure 1: Process Flow-Chart

The workshop was led by one of the researchers (CM) and assisted by a postgraduate student (MN), who created a transcript of the discussions (workshop protocol). The conduct of the workshop reflected the theoretical basis of its design. As described in the introduction, the two key aspects were paraphrasing and a two-step communication flow. Thus, the workshop was divided into two distinct phases. Phase 1 placed the eight invited speakers in an inner circle, facing each other and surrounded by the other participants, in an arrangement modelled on televised political debates (Livingstone & Lunt, 1994). Those in the outer circle were instructed simply to watch and listen the debate being conducted by the inner circle. They were informed that, in a second step, the discussion would be extended to everyone, using the same paraphrasing approach. In this way, the outer circle was able to gain a sense of the content, as well as how such issues are debated and how arguments are presented. The invited speakers had been requested to respond to an opening question: ‘How and where have you come across pain in your practice/research?’ The issues raised by each speaker were debated by the members of the inner circle, with the outer circle observing silently. This discussion lasted about 45 minutes.

Following this debate, all participants were invited to write down on post-it notes any thoughts that they had, either from their own experiences or arising from the speakers’ discussion. The post-it notes were mounted on wall charts, and then moved into thematic groups according to their content.

In Phase 2 of the workshop, which followed a break for refreshments, participants were divided into small groups of four or five people that were facilitated by the discussants from Phase 1. They were encouraged to discuss the issues raised by the inner circle debate and by the post-it notes, alongside their own personal experience and views about pain and dementia.

In round I part of Phase 2, participants were invited to discuss at their tables the question of what pain meant to them. After 15–20 minutes, they were asked to make any notes on the post-it notes provided, and to stick these on a large communal sheet of paper (see Figure 2), which everyone was then asked to view.

Figure 2: Results Thematic Analysis; Round 1: How would you describe pain and what it means to you? And Round 2: Issues encountered on engaging with people with dementia who are experiencing pain

(Source: Post-it Notes Workshop)

**Figure 2 about here**

In the round II of Phase 2, participants were asked a more specific question that invited them to reflect on their understanding of pain on engaging with people with dementia. This was designed to explore their professional or lived experience in this context. As before, they discussed the question for an agreed length of time and again attached post-it notes to another large sheet of paper (see Figure 2).

In addressing these questions, participants were encouraged to be imaginative and experimental in their responses. Altogether Phase 2 lasted about 60 minutes, and, at the end of the groups, the post-it notes were added to the initial display on the wall charts. Where it appeared appropriate, a regrouping of themes was made. The workshop ended at this point with general reflection and discussion, and participants were thanked for their time and for their contributions.

## Ethical considerations

This was an exploratory study with participants taking part either by invitation through word of mouth or having volunteered. All individuals, including those living with a diagnosis of dementia, had adequate mental capacity to contribute. They were all aware that their participation was entirely voluntary and that they were free to withdraw or leave the workshop at any time. The workshop approved by the Alzheimer Research UK. Participants were reimbursed of expenses.

## Data management

The conversation protocol and post-it notes from Phases 1 and 2 of the workshop constituted the data for addressing our first research question, i.e. if any new understandings about pain in dementia emerged from the workshop. The post-it notes were anonymous by their nature, so there was no potential to breach confidentiality. The data were taken away after the workshop for subsequent analysis.

The methodology of the workshop was also assessed in order to address our second research question regarding the appropriateness, acceptability and effectiveness of the workshop. No formal measures were employed, so this assessment comprised observation of the levels of participant involvement; informal estimation of their levels of comfort, interest and enjoyment; looking out for any signs of distress; and also in the informal comments made during and at the end of the workshop, as well as any feedback received afterwards, e.g., by email. In addition, written notes of the session were taken by a postgraduate assistant, which also comprised evidence about the success or otherwise of the workshop. These notes had been made for various purposes, including making a record of the inner circle debate in Phase 1 and issues around the conduct of the workshop; for example, if there were any problems with participants feeling uncomfortable or any issues with the catering or location.

### Data analysis

We followed the approach by Braun & Clarke (2006, 2019) conducting a reflexive thematic analysis of the initial group comments and post-it notes created during the workshop. This methodology was employed for the identification and analysis of patterns and themes based on the data set. The aim of this was to draw out the key themes about the nature of pain, its importance in dementia, how it may be detected and how it is best managed. The final array of themes was arrived at by means of discussion between the authors. This enabled us to address the first research question for the study. In addition to looking at the data as a whole, we compared the post-its from Phase 1 of the workshop with those from Phase 2 to examine whether there appeared to have been any shift in the responses of workshop participants during the course of the workshop.

## Workshop Results

### New understandings about pain

In relation to our first research question, we found that pain is best understood as a mediated experience involving multiple stakeholders, and that the quality of pain is not merely unpleasant but is also undefined. Findings will be presented for each of the two phases of the data collection.[iii]

In Phase 1, two main themes emerged: Pain as a clinical phenomenon, and Pain as a social relationship. Much of the initial exploration elicited and experimented with understandings of current medical practices and how these related to pain in people with dementia. Topics of these exchanges included the drive to objectify pain through protocols and professional standards, and how this becomes an obstacle because pain has an emotive quality can only be captured by less exact or non-verbal forms of expression. Some important contributions are listed below:

> *… the medical/clinical model of pain that fails to take account of complexity* (Participant F).

> *Current regimented institutional settings make it difficult for professionals to function as human beings because they discourage feelings, and quality measures do not accommodate gut feeling* (Participant K).

> *Palliative care is a good example of the need to be instinctive as an element of ethical practice* (Participant V).

> *Evidence-based practice is important but limited at individual level and does not take the broader picture into account* (Participant T).

> *Medical practice discourages the use of instinct* (Participant J).

By establishing this tension between 'intuition' and professional protocols a common obstacle, the exploration opened itself up to a new turning point. One participant, who had previously remained in the background, seized the opportunity to speak at greater length. Suggesting that this tension could be handled differently, she explained that she works outside institutional care, and mostly on a one-to-one basis with her clients: "I am able to work as a team with the family of the client and the client themselves. Based on these quality interactions, I can develop a deep understanding of the individual, which is needed to understand pain." Participant E From here, the exploration entered a second stage, in which pain was considered as a two-way relationship, and participants reflected on what such a relationship should look like to ensure that pain was understood. This shift involved testing out the notion of two-way relationships in broader terms of the need to listen and the ability to understand the other person. This in turn was linked to the idea of building a relationship or connection at human level, recognising the person as an individual rather than merely as a patient or as someone experiencing pain. This broader view was considered crucial in understanding what pain meant to that person.

> *Other people told me what would be best for my father [who had dementia], and no one listened to him* (Participant J).

> *Reflecting on my professional practice and it's important to have the courage to listen without fear of litigation* (Participant K).

> *If we cannot be human together, we cannot recognise pain* (Participant F).

> *We need to build 'connections' into broader frameworks* (Participant T).

As mentioned above, in Phase 2, participants were invited to discuss two specific questions in two rounds (round I and round II) of discussion. In response to the first question in round I ('How would you describe pain and what does it mean to you?'), there were 150 responses recorded. A sentiment analysis on polarity (positive, negative, neutral) of the responses was applied to illustrate some variations in the clustering of certain descriptors over others (on this methodology within a context of pain, see Tighe et al. 2015) The analysis showed that about 99 (66%) were negative, using descriptors like *hurt*, *sharp* or *unpleasant* to characterise pain. Other words used included causes of pain like trauma, injury or disease, and impacts such as exhaustion, fear or loss of balance. The remaining responses were either neutral or technical descriptions (e.g., *complex*, *expression* of *circumstances or unusual* N=40; 27%) or positive (e.g., *love*, *peace* or *pride* N=11; 7%). Most of the responses were single-word descriptors, which perhaps indicated that, at this point, participants were taking quite a narrow view of the meaning of pain.

In the second round of Phase 2, participants were asked to reflect on their understanding of pain on engaging with people with dementia. There were 131 responses in total (see Figure 2). Two findings in particular stood out from this session. First, people more often described pain in sentences or short phrases rather than in single keywords.

Second, the meanings attributed to pain were more evenly balanced and included positive descriptions of pain in childbirth, sport and sexual encounters (N=44; 34%). In a notable change, some comments referred to the role of pain in the interaction between persons with dementia and their carers; for example, in providing support or helping to interpret the pain, accepting their self-evaluation of pain or providing love and tenderness. Many comments also rejected any easy classification of pain, describing it instead as challenging or undefined; beyond simply being an unpleasant emotion, pain was seen as part of a larger process.

To summarise, in round II of Phase 2, discussion of the meaning of pain within the context of dementia shifted noticeably, starting to place more emphasis on how pain involves a social relationship and interactions between people, not merely a simple biological phenomenon.

## Discussion: Towards a New Understanding of Pain

The central aim of this research was to employ an experimental approach to develop new conceptualisation of pain in people with dementia. The discussion in both phases of our workshop indicated that a narrow definition, such as medical terminology that typically defines pain as an unpleasant bodily sensation, fails to grasp important aspects of the meaning of pain. In particular, medical definitions fail to acknowledge the relational nature of pain; in other words, because pain is seen as a kind of bodily experience, which can be accessed more or less directly and objectively by the affected person, it is viewed as unmediated. However, the present findings suggest that pain should instead be understood as mediated, because it depends jointly on our nervous system, our brain, how we feel about things and how we relate to others. By mediated, we mean that pain ‘exists’ and acquires its meaning within this network. As evidenced through our experimental theoretical method, we could show that pain is not owned or produced by the body speaking for itself, individual thoughts and feelings, but the making of the meaning of pain rests on a distributed agency (Garud & Karnøe 2005). As such, we can conclude that pain in general, but especially in more advanced stages of dementia acquires a stronger relational emphasis as it requires witnessing and advocating – given the increasing communication difficulties as dementia progresses. Additionally, it can be said that what pain introduces into this network is not simply a negative framing but an interruption of meaning-making the consequences of which are not easy grasped. The disruptive quality of pain can be enticing, because it presents something new and surprising, but may also lead to frustration and fear if the making of meaning of pain is impaired for any length of time, because it remains unmediated. Research shows that such unresolved interruptions of meanings lead to a reaction on itself with a spiralling effect known pain catastrophising (see Quartana, et al. 2009). We can conclude, then, that pain can be defined as an interruption of the socially mediated process of bodily meaning-making. Such a definition of pain suggests that future forms of pain assessment need to recognise that pain is mediated (see van Hout et al. 2023). For instance, to one person the interruption of the socially mediated process of bodily meaning-making might imply notions of failure, for instance, failing to function as a provider for their family, whereas another person might consider this failure as a source to be a potential burden for others. Such different meanings of pain will not only impact on people’s awareness, but also on their understanding of the severity of the pain. These considerations have two further implications. The emphasis on pain as a socially mediated process puts greater emphasis on its ‘inter-subjective’ quality, which means that the diagnoses of pain not only involves the person expressing pain, but also the person interpreting this expression co-producing pain as an epistemic object. Approaches like person-centred care, stress such a reflective quality in diagnosis and treatment (on such recent developments, see Wigert et al. 2021). Furthermore, this revised definition of pain is not only helpful within a dementia context, but also contributes a wider understanding about the changing importance of pain in contemporary society. For instance, if pain remains unmediated, it is likely to increase in importance, which is why some authors speak of a pain epidemic (Sessle 2011, 2012; Rosa et al. 2021). Zajacova et al. (2021) could demonstrate in their research that the experience of prolonged pain has been increasing across all age groups and genders in the US in the past 20 years with the highest increase among men between 20-40 years old. Such findings reveal that pain cannot simply be associated with old age, but raises much more profound question about the mediation of pain in society. This would be an important area of research for medical practitioners as well as social scientists, because the evolution of pain, e.g., the rise in awareness of bodily sensitiveness, the social acceptance (or lack of it) of interruptions to bodily meaning-making is in co-variation with changing societal contexts (see Morgner 2022).

Our second aim was that we wanted to test a novel method in terms of it being appropriate, accessible and effective to unravel implicit and tacit theoretical heuristics.

The workshop appeared to be successful in terms of appropriateness; it was not difficult to find speakers from diverse contexts, and all participants acknowledged the importance of the issue of pain in dementia. In relation, to accessibility, the workshop progressed smoothly throughout and active contributions were made by all participants. Any initial hesitancy among participants about the inner and outer circle methods in Phase 1 was assuaged by reassuring them that they would have time to contribute their views later. Participants with a diagnosis of dementia, along with their relatives, clearly welcomed the opportunity to contribute. They would actively take notes of the discussion from phase 1 and although they sometimes needed encouragement to speak out, individuals with dementia made important contributions and appeared comfortable in doing so during phase 2. While one or two of these participants occasionally needed a brief rest, no-one withdrew from the workshop because of distress. There were numerous positive comments, including informal feedback received at the end of the event. Finally, its effectiveness lies in its ability to deepen our understanding of pain in dementia, and the findings suggest that assessment and treatment requires a more interdisciplinary approach involving neuro-psychological-sociological inputs. These findings suggest that this experimental-theoretical format has contributed to the development of a new understanding of pain through an active contribution of participants from different social context by devising an accessible methodology based on performing arts, art education and communication studies.

## Strengths and limitations

Based on established theory from the communications literature and on previous work with analogous stakeholder groups, this novel study proved successful in attracting diverse participants, including people with dementia, and produced new theoretical insights into how pain and dementia can be understood. The methodology appears robust and may prove more effective than reviews of existing literature.

While the sample was small, reflecting the relatively small population of people with dementia, the participants brought a broad range of experience of research and dementia and end of life care to the study. Other limitations include the extensive preparation and the longer workshop duration as compared to the typical focus group, which means that some individuals may become fatigued before the end of the session, and the need for careful management of the environment for the participants. We had one participant who left the session during the break, due to his failed hearing the device and in combination with the acoustics of the room.

## Implications

The study is important for future research on pain in dementia and research on pain in general as it provides a methodology that could be used for further enquiry, for example in exploring further what methods are tried and tested and may be useful in practice. The relational mediated aspects of pain require more attention in future research designs. We have also shown that people with dementia can contribute well to discussions about pain, despite its abstract nature and difficulties in discussing it. Therefore, future studies should facilitate further involvement of people with lived experience as much as seeking proxy views from carers and professionals.

Our research also noted that less exact or non-verbal forms of expression should be considered in the diagnosis of pain. As noted, existing measures heavily rely on verbal or written means; however, the is an emerging area of research exploring alternative modes of expression, such as using visual art or music (see Padfield et al. 2018). While such art interventions have notable effects on pain treatment, they have not yet been considered for assessing a person’s understanding of pain.

Staff training on pain in dementia is somewhat limited and tends to focus on the use of pain rating scales, which as we have argued above have considerable limitations. Our experimental methodology could equally well be applied as a training method, where professional staff could learn much from the contributions of participants with dementia. This would help enhance their confidence in supporting people with dementia who may be in pain, but may also be applied to topics beyond pain (see Agarwal et al. 2020). This emphasis on staff training is also justified, because the recognition of pain is not solely on an individual expressing pain, but adds weight to the caregiver to interpret verbal and non-verbal expressions appropriately or even to assist the person in expressing pain (see Weissman & Matson 1999).

Finally, our theoretical-experimental method also opens up broader questions about the state of theorisation in the medical field and the need to intervene in the mostly implicit practice of medical theory (see also Neilson 2016). Our method will equip medical practitioners and other clinical professionals with a robust as well as creative methodological process to enhance the formulation of medical concepts. This is an area where medical theory can benefit from recent debates in the field of social theory (see Swedberg 2012).

## Conclusions

This study has used methodological interventions derived from museum and communication studies to develop a new theoretical-experimental approach to explore pain and its expression in people with dementia. This has led to a new definition of pain as an interruption of the socially mediated process of bodily meaning-making. Furthermore, we have emphasised the social, relational quality of pain that sits alongside its biological origins, and from this arises the notion of witness and testimony on the part of others as an essential component of responding to and managing pain in dementia. This means that future research does not only need to consider the expression of pain, but also its interpretation, for instance, to what extent professional staff are able to engage in this interpretation. This is in contrast to the recently revised definition of pain by the International Association for the Study of Pain, which stated that this relational part is “not an essential component of the definition” of pain (Raja et al. 2020: 3). Finally, our experimental intervention reflected upon the process of generating theory by making the various steps and considerations explicit as well as critically reflecting on intervening into this process. We therefore contribute to a yet unexplored field of research, which considers the practice of medical theory, i.e., how concepts and theories are generated in the medical field.

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[i] This negative conception of pain also overlooks a broader spectrum of meanings that can have a more positive connotation, for instance, the pain of childbirth or sexually stimulated pain.

[ii] Others have noted that the overt medicalisation of pain neglects that pain is a meaningful construct that makes us human (see the chapter 'The Killing of Pain' in Illich 1982). Likewise, Ernst Jünger (2008, p. 3) noted in his essay *On Pain* its very foundational notion, but not as a mere bodily sensation, but as a relational construct: 'Tell me your relation to pain, and I will tell you who you are!'

[iii] The notion of a mediated experience stresses the mutual involvement of the 'knower' and the 'known' within a context of great complexity (see Morgner 2019).