

**Running header: BEING IN PAIN:**

*Using images and participatory methods to explore intercultural understanding of pain*

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**Abstract**

Pain is socially and culturally experienced. This chapter builds on previous research into the value of visual images for communicating pain in the UK, which evidenced ways in which images can improve doctor-patient interaction. It will discuss ways in which photographs co-created with people living with chronic pain can be catalysts for discussion of pain and suffering in a range of cultural contexts, including higher education and healthcare training. It draws on a pilot project in Delhi, India where images were used as stimulus to dialogue and exploration of shared understanding of pain and current work in UK higher education using visual and other participatory methods. Students have a chance to work with and discuss images which depict qualities and characters of pain. Through seeing and hearing about patients' experiences of pain, students learn about the commonalities and diversities in people's experiences of their bodies and minds and how these impact on lives. As future health professionals, their own responses to this are important. Chronic pain can be a disabling condition leaving people vulnerable, with their sense of self and how they are seen by others threatened. People living with pain have to (re)negotiate their identity, with themselves and others, to see who they can be, as well as what they can do in this new state. Exploration of this through visual arts and verbal participatory activities can provide otherwise untapped insights and understandings of the human condition and its diversity. Exploring ways in which this approach could be extended to and adapted to other contexts are part of our future plans.

**Keywords:**

Art  
Pain  
Photography  
Disability  
Identity  
Visual images  
Communication  
Participation  
Reflexivity

## **Introduction**

Accepted as a major global health challenge, pain is socially and culturally experienced (Bourke 2014). Pioneer of narrative medicine, Rita Charon, calls it ‘the central dilemma of our age’ (2016). Known to be under-reported, under-recognized, and under-diagnosed (Lacasse et al 2016), pain places an economic burden on countries as well as a heavy burden of suffering on individuals. It is subjective, largely invisible to medical imaging, and remains difficult to share or constrict into the standardised verbal or numerical scales commonly used. Persistent pain (i.e. pain that has lasted longer than three months with no resolution) has no biomarkers, so diagnosis relies on patient narratives, once other causes have been ruled out. Yet there is limited language with which to express it and it remains stubbornly resistant to verbal language (Scarry 1985). While there are approaches for managing persistent pain, there are currently no ‘cures’. Chronic pain therefore becomes a disabling condition and the link between pain and disability is important to recognize. Pain and its impacts demand that we pay attention to the extreme experiences of another, that we attempt to cross the chasm separating their bodies from ours with limited tools available for navigation. With poor communication cited as one of the main causes of inadequate management (Kimberlin et al. 2004, Yates et al. 2002), it is urgent that communication between those living with and those witnessing or treating pain are improved and that central to healthcare students’ and continuous professional training are the intersections between the social, cultural and emotional challenges of persistent pain. Following calls from Craig and Williams (2016), Biro (2014) and others, the International Association for the Study of Pain (IASP) has recently changed its definition of pain, to include social experiences (Raja et al 2020)<sup>1</sup>. However, little is known about how these and the way they are represented vary across cultures. Transcultural tools are needed to explore the intersections between culture, emotion and the body within the experience of ‘being’ in pain and in the world.

The chapter will discuss ways in which visual approaches to communication, such as photographs co-created with people living with pain in a range of cultural settings, can be catalysts for discussion and increased understanding of the subjective experience of pain and suffering within higher education, particularly within healthcare training. It draws on work in the UK and a recent pilot collaborative project in Delhi, India, where visual images and other participatory methods were used as stimulus for dialogue and an exploration of shared understanding. The aims, methods and results will be discussed along with their implications for practice and knowledge exchange within healthcare and higher education. The different methodologies used to collect data drew on alternative systems of knowledge which did not rely solely on verbal language and which, we argue, could be used as a basis for teaching and learning in a range of settings. These methodologies open up spaces within which to reconstruct new meanings of pain while deconstructing some assumptions commonly held about pain within medical contexts. These understandings of the subjective experience of pain and its expression could radically change the way that the topic is discussed in the clinical encounter.

In the early years of medical training, much emphasis is on the necessity to absorb huge amounts of information with less on understanding the patients’ experience, the students’ own responses to clinical interactions, or critical thinking around the context in which healthcare happens. We believe that students can benefit from being introduced to the complex factors which contribute to pain and its management at an early stage. One way of

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eliciting relevant narrative and facilitating emotional disclosure, which otherwise might not happen in the consulting room, is the use of visual objects and photographs which build on photo elicitation techniques (Radley & Taylor 2003). This can give future health professionals a nuanced understanding of the complexities of the pain experience and provide them with alternative ways of talking about pain in the clinic with the potential to shift their approaches to a more person-centred mode. The chapter argues that raising awareness of the complexity of pain and the myriad ways in which individuals interpret, feel and witness pain, can contribute to intercultural and transcultural understandings of its disabling impact.

### **Participatory methods and the reflexive turn**

While focussing on a very specific example of the use of innovative and participatory methods of interaction with patients (such as non-verbal visual media - objects and photographs) in discussions about their pain and its effects, we also discuss novel ways in which verbal conversations can be used in equally flexible ways. Shifting from the typical clinical 'case history' mode of communication and towards the powerful language someone chooses to describe their experience (words, phrases, metaphors) can help us learn how they view their situation .

The use of these techniques for pain consultations can be seen to fit into a family of approaches to talking to people, collecting 'data' and understanding what is going on for them. Within anthropology, where the aim is to understand people in their 'natural' settings, without 'disturbing the field', participatory approaches have been common for some decades. Anthropologists classically use 'participant observation' (part of ethnography) as their main method. Here they immerse themselves in a real situation to watch and listen to what people do and say in order to learn about them and their society. They also use very 'person-centred' types of conversations – open flexible interviews, where the agenda is set more by the participant than the researcher. This enables a deep level of mutual understanding to emerge centring on the person's choice of topic, the emphasis and priorities they give and the kinds of language they use. This brings subjective, individualised perspectives to the surface, rather than generating the objective bounded answers that a structured interview might.

Importantly, the researcher's own role in such flexible conversations, and indeed in interpreting what is said, is crucial (Coffey A 1999). Conversations are understood as co-produced joint enterprises. This shift to recognising the role of the researcher/interviewer in the encounter is called the 'reflexive turn' (Cohen 1994, Aull Davies 1998). Surprisingly perhaps, there has not been much recognition that this shift from an assumed objectivity to an acknowledged subjectivity could and possibly should, happen in other types of interactions – such as health professionals' clinical encounters or student-teacher relationships.

Clearly this reflexive approach would not be appropriate in every interaction between a health professional and a patient, but there might be a place for it when dealing with complex, chronic, and potentially stigmatising conditions such as pain or disability. In these situations, very personal, difficult aspects of identity, mind-body relationships and feelings of not being believed or understood are common. These complexities, which threaten the internal integrity of the person, may require a more collaborative and reflexive approach from clinicians, demanding more of the health professional than just being reflective, which has been advocated widely (Schon 1991). Both reflexivity and reflection are important.

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A new generation of healthcare professionals, if taught about these approaches and encouraged to recognise their subjective selves as part of clinical encounters, might provide improved, more empathic services to patients who are in pain, disabled or have other complex, poorly understood health conditions. The use of visual and more flexible innovative verbal techniques could be added to the health professionals' toolbox. Later in the chapter we will come back to the potential application of some of these concepts in higher education, once we have described the study.

### **Visualising pain project in Delhi, India**

The project, *Visualising pain: towards an international iconography of pain to improve the communication and management of pain in India and the UK* (<https://deborahpadfield.com/Visualising-Pain>), on which this chapter draws, was a collaboration between the authors and partners in Delhi, India<sup>2</sup>. The study built on previous research into the value of visual images for communicating pain in the UK, which evidenced ways in which visual images can improve communication and doctor-patient interaction around pain (Padfield & Zarezevska 2021, Padfield et al 2018, Ashton-James et Al 2017, Semino et al 2017, Padfield et al 2017). Although in India there remains a scarcity of pain management services, particularly in rural areas, the recent increase in life expectancy and economic growth has resulted in a rise in people seeking help for persistent pain (National Research Council, 2012). Communication about pain raises significant challenges in a country such as India with its diversities of languages, ethnicities, religions, cultures and beliefs (Doshi, 2021). Although the national language is Hindi, people communicate in nearly 114 local languages with 18 official languages (Doshi 2021). If a healthcare worker and patient do not share the same language, miscommunication and misinterpretation can result, impacting on the clinician's understanding of the patient's situation and therefore the management offered. Healthcare in India is syncretic, someone experiencing pain may seek help from many different types of practitioner with diverse understandings of the body, mind, spirit or soul and how these interconnect.

The visualising pain project sought to explore, learn about and potentially address some of these challenges both in India and within the multicultural populations of the UK. What could we bring to and learn from each other? Additionally, it sought to explore whether it would be possible to extend and reinterpret the range of images of pain co-constructed in the UK, to develop a 'trans-cultural iconography' for pain able to resonate in diverse cultural contexts. Are there commonalities across cultures in how pain is experienced and described (visually or verbally) or will the images and conceptions always be culturally dependent and distinct? We aimed to explore whether aspects of social and cultural conceptualisations of pain may be universal, while also identifying aspects which are culturally specific. Could this have mutual benefit, enhancing cross-cultural understanding and perhaps providing an opportunity for learning across settings globally?

We ran a series of workshops over two weeks in May 2019 in Gurgaon, Delhi consisting of: 1) a group participatory creative workshop, (for a range of stakeholders from mixed gender/faith/language and educational levels, including people living with pain, their carers and families, healthcare workers, artists and academics) 2) a series of individual photographic workshops co-creating images of pain with Deborah Padfield (DP), alongside sessions with Mary Wickenden (MW) exploring individuals' language about their pain using mind maps and 3) a final celebration and sharing event with the original group and new participants a week later.

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The Participatory creative workshop was divided into discrete sections with ice breaker sessions, painting workshops where participants explored textures and colours for expressing both pain and relief from it (HG), group mind-mapping sessions reflecting jointly on their pain- generating key words and phrases and other creative activities (MW) and individual photographic workshops where participants worked in pairs to give visual form to their hidden and subjective experiences of pain (DP and MGG).

Barriers quickly dissolved and participants shared their experiences and ideas with each other surprisingly easily, perhaps bonded by their shared experience of pain? The use of imagination, visual metaphor and non-verbal means appeared to enable participants to articulate what is often difficult to put into words. The making of visual and tactile material catalysed free and open discussions around pain during the mind mapping sessions and included social and cultural conceptualisations of pain, facilitating intercultural communication between participants.

In the week between the group workshop and the celebratory event hosted by SS<sup>2</sup> and AM, artists DP and MGG worked individually with four volunteers to co-create a series of photographs which represented their unique experience of pain.

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It is important that these images were co-created, the pain sufferer and artist working together (Padfield & Zakrzewska 2021), thus avoiding appropriating the experience or cultural understandings of others. Participants were invited to bring objects to the sessions which they felt communicated aspects of their experience through colour, texture, symbolism or personal association, such as rope, ice, glasses or containers. These were experimented with during the individual workshops as we played with composition, lighting and/or performance. An audio-recording was kept as a record of the process and what participants felt important to communicate. The images were edited between sessions by MGG and DP. These images were brought back to subsequent sessions and the images refined. In the final individual session, participants co-created images expressing relief from pain. The aim was to avoid leaving volunteers with images trapping them within the worst part of their experience, but to move to more positive visualisations of the possibility of relief. What was interesting in the Delhi workshops was how some participants chose to incorporate relief from pain into the same image that communicated intense pain – something not witnessed with participants in the UK. It suggested there was more of an acceptance of pain emerging through the Delhi images, but this would need further testing in a larger cohort. What was observable was that the images and image-making process catalysed rich explorations of pain and its impact which would have been difficult to capture in words alone and which revealed participants' intense, diverse and personal relationships with pain.

In addition to the individual photographic imaging making workshops, each of the four volunteers undertook a task with MW which might initially seem diametrically opposite to the visual task. This involved making an individual 'mindmap' of words and phrases arranged on a single page by the participant, in conversation with MW. The invitation was to 'tell the story of your pain in any way you like – by filling up this page'. The idea is to extract the 'semantic network' of meanings that the person has on the topic (Berger & Luckman 1967). This will be influenced by their individual personality and experience but also by their cultural context, languages and traditions. All four volunteers participated

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enthusiastically, albeit in contrasting ways and filled their page fully. Some used colour and shape to draw boundaries and links between the different words and phrases they had arranged on the page. They were encouraged to use words from any language (as all were at least bilingual, with English not their first language). The conversations were recorded and the content of the four mindmaps analysed thematically as group data and presented back to the group in an anonymised format, drawing out similarities, differences, key concepts and messages.

Finally, the group movement workshop, led by NS with SS, based on 'theatre of the oppressed' techniques (Singh et al 2019) with which we began the final celebratory event, used bodily movement and physical gesture to access and communicate subjective feelings. Through omission of words (this first hour was enacted in silence), both mutual respect and a level playing field was created between all participants. It was an ideal way to begin any participatory workshop and silence emerged as an equally useful consultation tool to sound.

### **Alternative routes to knowledge creation**

The use of innovative visual, verbal and participatory methods to understand someone's experience seems to have potential for opening up clinical encounters and making them more personal and tailored to learning about individuals' unique experiences. It is impossible to completely understand the experience of another, but understanding maybe enhanced by using person-centred approaches. Visual techniques like image making with art materials, photography and or free-flowing verbal maps have the potential to release intense feelings which are otherwise hidden or unexpressed. They may also reveal people's underlying beliefs and explanations of their pain, why they have it, what has caused it and what may relieve it. Medical anthropologists talk about individuals' 'explanatory models' of health and illness episodes (Kleinman 1988). The way we all conceptualise periods of relative wellbeing and distress is bound to be influenced by the beliefs and assumptions we have about the nature of our bodies, minds, souls and the world we live in. These explanatory models may have some universal elements and some that are linked to cultural contexts. In fact, many contemporary theories about the nature of the body and its relationship with identity, emphasise that the body is a social as well as corporal entity (Shilling 1994). Csordas sees the body 'as subject in everyday life experience and as object in science' (Csordas 1990:35)

People who have bodies that do not conform to the 'normal expectations' either because they are painful or do not look or perform in a typical manner (in the case of disability), may have complex relationships with that body. Inhabiting such a body, may be open to criticism both from its owner and from others. Of course, for many people who have a body that is seen as in some way different, this gives them a strange cognitive dissonance, because that body is 'normal' to them (Watson 2002). Thus, it can be frustrating that others cannot understand what living in that kind of body is like. People experiencing chronic pain and other chronic conditions or disability often feel left out and 'liminal'. They feel they no longer fit in in society and are misunderstood (Murphy et al., 1988, Hughes & Paterson 1997).

The way that the participants in the workshop talked about their pain, and made images revealed narratives which were clearly part of their efforts at making sense of it. The literature about the role of narration in identity formation is also relevant. We all tell stories about our lives in order to put them into some kind of order and to cement our view of

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ourselves (Frank 1995 Clandinin & Connelly 2000).<sup>3</sup> The participants in the pain workshops in India told powerful stories of pain through a combination of images and words.

### **Use of images and participatory methods within higher education**

Images can provide a powerful and immediate means of communication, both within health contexts but also within higher education teaching. A photograph has shape, texture, colour, surface, symbolism and a process behind it, which has led to the final image and how we read it. In a study offering cameras to in-patients, social psychologist, Radley, observed how photographs elicit narrative

*‘the photographs gained their meaning from the act that produced them; they were not meaningful only in the sense of their pictured content’* (Radley 2010, p. 270).

Here photography can be understood not just as a medium but as a process, *‘a way of making known and shaping experience’* (Radley 2010, p. 270). In the pain clinic, when the images (as laminated cards) are offered to other patients who were not involved in creating them, the fact that they have been co-created by real pain sufferers appears to increase clinician patient rapport (Williams 2021, Ashton James et al 2017). Within teaching, the images allow students to access something of the multi-layered experience which led to the final image which cannot necessarily be accessed via verbal language alone. It also encourages them to consider what type of photograph they might create themselves, integrating their intellect with imagination, conscious with unconscious and thus encouraging a reflexive approach, as discussed above. The photograph itself is a construct, but even in this age of digital modification, we ascribe an authenticity to its ability to document. It could be argued it is the perfect medium for validating and making real, the invisible, subjective and slippery experiences of others. Teaching using the pain cards offers healthcare students an additional tool with which to understand and communicate with future patients, simultaneously introducing them to the multifactorial, sometimes seemingly illogical and dynamic nature of pain experience. The images, by their nature, are as bewildering and surreal as the experiences they reflect, with many pointing towards isolation, loss and change of identity. Drawing on Charon’s methodologies within narrative medicine (2017), the cards provide a way of bypassing the generic questions at the start of a pain consultation and eliciting instead living, urgent discussion of pain and its impact. They appear to catalyse emotional disclosure relevant to the prolongation and intensity of the pain (Padfield et al 2017, Padfield et al 2018). In addition, they create a shared space between healthcare practitioners and patients within which to negotiate. In a similar way, in the classroom images can provide a shared mediating space between a pair of students, through which they can discuss their own experience, triggered by the image. A frequently used exercise involves inviting students to select one image from the pain cards which resonates for them. Students are paired and asked to discuss that experience with their partner, using the image as a stimulus. They are instructed not to share details of the experiences discussed with the wider group, but share how they found using images rather than words as a starting point. Students can relate this to the clinical setting and ways in which the process can be adapted to improve intersectional understanding. Furthermore, in mixed cultural group discussions, many students offered valuable personal insights and interpretations from healthcare systems and practices in a wider range of contexts. The images thus enable an exploration of the way visual stimuli can open up discussion and sharing including intercultural experiences to generate new knowledge.

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The examples in this chapter of innovative ways of improving interpersonal understanding have been in the health arena. However, they could equally be applied more broadly to the education and training of students and professionals in other disciplines. The images have been used for example, within photography, community arts practice, art history and Fine Art teaching in further and higher education. Here they have acted as triggers to discussion around alternative forms of portraiture, the co-created photograph as a mechanism for collaborative approaches to portraiture and for understanding images as relation building. They have also been used with mixed cohorts of medical and humanities students to open up discussion of identity, empathy, metaphor and ways of understanding the experience of others and to spark debate at conferences and public events.

It is hard to think of a subject area or profession where better understanding between people and more nuanced ways of interacting would not be helpful. Thus, the reflexive turn would seem to be applicable in many arenas. A university lecturer or school teacher, who shows empathy, personal interest in her students and makes efforts to listen responsively to their ideas will find the students more open, questioning and responsive. Thus, this slight shift towards a more subjective, experimental and reflexive approach to interaction when teaching might be useful. It seems that being 'professional' does not necessarily mean being objective. Some would argue that objectivity is actually impossible, even in the positivist hard sciences where rationalism is thought to be king! Perhaps what is needed is some reflection on what kind of subjectivity can be useful?

### **Conclusion**

From the small pilot in Delhi, we uncovered remarkable similarities of experience and expression of pain as well as divergences. Many of the images shared metaphors and conceptualisations of pain with those co-created in the UK, revealing recurring themes, such as constraint, isolation, extremes of temperature, medication as a contested issue and loss/change of identity. This suggests that there may be some universal aspects of living with pain and its disabling consequences which can be expected cross-culturally. Equally there were examples of specific cultural interpretation and conceptualisations of pain, with acceptance of pain being more evident in the discussions and images co-created in Delhi than the UK. However, this is to generalise and the cohort was very small, so all we can safely conclude is that this is an area for further exploration in the future with some potential implications for clinical practice across cultural settings.

Using these individually focussed visual and verbal methods enables subjective experience to be revealed in a more personal way than through a standard clinical tool. The unique aspects of a person's pain, can have lessons for a broader range of healthcare situations. They demonstrate that a person-centred and reflexive approach, requiring commitment from the health professional to a subjective orientation, rather than aiming for an unreachable objectivity, can be useful. These approaches result in patients feeling listened to and understood in a deep way, which, because their pain is invisible and untestable, is often denied to them. Pain can feel indescribable and beyond words. Visual methods enable people to express the nature of their pain without words, which in turn, rejuvenates the language used around pain. Through using adaptations of these person-centred and negotiated process clinicians could better understand their patients.

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In a similar way, we found that through images students often disclosed unexpected insights into the value of images to a clinical encounter and to negotiating meaning and sense-making across differing perspectives. Seeing and hearing about patients' experiences and images of pain expressed visually or verbally appeared to enhance their learning about the commonalities and diversities in people's experiences of their bodies and minds and how these experiences impact on lives. At the same time, it encourages students to bring examples from their own experience of healthcare in diverse cultural contexts. Exploration of these ideas through visual arts and participatory verbal activities can provide students with otherwise untapped insights and understandings of the human condition and its diversity. Exploring ways in which this approach could be extended to and adapted to other settings within further and higher education are part of our future plans

The key message in the context of healthcare students' education is that the use of reflexive approaches, such as multiple types of visual media and verbal free expression, can unlock deeper levels of understanding for both the patient and the professional (or student and teacher). Reflexivity, with its ability to penetrate into human subjectivities as well as inter-subjectivity can contribute to creating new knowledge systems in healthcare education. Recognition of the subjective aspects of both partners in the clinical or other professional encounter can enhance relationships benefitting intercultural understanding and supporting an argument for the development of new knowledge systems to enrich higher education.

### **End notes**

1 The IASP definition for pain has been accepted by healthcare systems globally since 1979 as: '*An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage*'. The IASP has updated its definition in 2020 to include social aspects of pain and can be summarised as: '*An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.*'

The notes (Raja et al 2020) assert:

- Pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors.
- Pain and nociception are different phenomena. Pain cannot be inferred solely from activity in sensory neurons.
- Through their life experiences, individuals learn the concept of pain.
- A person's report of an experience as pain should be respected.
- Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being.
- Verbal description is only one of several behaviors to express pain; inability to communicate does not negate the possibility that a human or a nonhuman animal experiences pain.

2 Project partners in Delhi, identified later through initials:

Dr Anubha Mahajan, founder India's only pain survivor support group, *Chronic Pain India* (AM)

Mariana Gomes Goncalvez , artist, UK/Portugal (MGG)

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Himani Gupta, artist, Delhi (HG)

People living with pain from across India

Navjeevan Singh, co-founder Medical Humanities Group & Former, Director Professor of Pathology, UCMS (NS)

Dr Satendra Singh, co-founder Medical Humanities Group & Former, Director Professor of Pathology, UCMS (SS)

3 It is worth noting that Sara Wasson, conversely, argues narrative fragments rather than coherent narratives are more reflective of illness experience (Wasson 2018).

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### **Legends for images:**

All photographs were co-created with people with pain:

Fig 1 Deborah Padfield with Satendra Singh from the series *Visualising Pain*, 2019, archival digital print © Deborah Padfield

Fig 2 Deborah Padfield with Anubha Mahajan from the series *Visualising Pain*, 2019, archival digital print © Deborah Padfield

Fig 3 Deborah Padfield with Meenakshi Venkataraman from the series *Visualising Pain*, 2019, archival digital print © Deborah Padfield

Fig 4 Deborah Padfield with Swati Agrawal from the series *Visualising Pain*, 2019, archival digital print © Deborah Padfield