***Mirrors and shadows:***

**Photography as a way of sharing pain experience in medical pain consultations**

**Deborah Padfield**

**(Adapted from an original article first published in the inaugural edition of Qualia, 1)**

**~~The Mirror~~**

Photographic art, like the mirror, can allow us to see ourselves, by freezing time to allow reflection. In the context of pain encounters however, perhaps we need to question what it is we see when we look at another in pain: is it them or ourselves - their pain or ours? I believe the polysemy of photographs can help prevent us from seeing only reflections of ourselves and encourage us to tolerate the complexity and ambiguity of, in Susan Sontag’s words, *‘the pain of others’*[[1]](#footnote-1); the pain of not knowing, of resisting the desire to ‘solve’, of accepting not having an answer. The multiple interpretations evoked by an image force us to check and re-check via the image that we are understanding each other and encourage us to grapple with sensations and feelings not our own.

Building on Elaine Scarry’s seminal work on pain,[[2]](#footnote-2) community artist and academic Petra Kuppers describes how ‘*Pain flees outward toward imagination, from the dense matter of bodies to perception itself…*’[[3]](#footnote-3) It is possible we can employ imagination and the photographic plate, itself a mirror, to re-integrate perception, image and language reflecting back to us the ways in which we, like all substances, have ‘relations which express all the others’, making us, in Stafford’s words, ‘perpetual living mirrors of the universe.’[[4]](#footnote-4)

**The Shadow**

Scarry asserts that

‘physical pain – unlike any other state of consciousness – has no referential content. It is not *of* or *for* anything. It is precisely because it takes no object that it, more than any other phenomenon, resists objectification in language.’ [[5]](#footnote-5)

It is arguable that many persistent pain states *do* have relationships to external events or objects which exacerbate, intensify and complicate the pain. These pain states could be seen as ‘*of* or *for’* something. Pain itself could therefore be conceived as a shadow referential of other objects and relations. The shadow inhabits a realm of obscurity, of concealment, of absence of light and visibility. It has a relationship to an object other than itself, rather than being a tangible object. It eludes our grasp, it evokes ambiguity, elusivity and fear: it is consequently the perfect metaphor for pain.

I believe the spontaneity of the creative process allows it to touch the shadows, to reach the unconscious and via the image bring elements to the surface to be discussed and shared. It exposes what needs to be retrieved and reflected on, bringing it into consciousness and the daylight of the consulting room.

This chapter examines the potential for photographs to improve interaction in the medical pain consulting room through the example of a recent Fine Art Medical collaboration at University College Hospital, London, UK. It will focus on one specific series of images – the *shadow sandwich* – exploring the multiple interpretations it elicited, which, arguably, parallel the way multiple experiences of an encounter can co-exist in the consulting room.

**~~The need to communicate and find a shared Rhetoric for Pain~~**

Chronic pain and musculoskeletal disorders are associated with some of the poorest quality-of-life indices. This complex phenomenon we call pain relies on communication for its diagnosis, and is therefore unlikely to be resolved by techno-centric or pharmaceutical medicine alone. With no biomarkers, pain remains a subjective sensation relying on the patient’s story, and dependent on the sufferer being able to express it. In this context any tool that can help elicit a patient’s story has potential to benefit patient care. Medical Anthropologist ArthurKleinman argues for the value of integrating the ‘physiological, psychological and social meanings’of pain and illness.[[6]](#footnote-6) Narrative medicine is one means of achieving this as it

allows the patient to be heard, begin healing, and may be just what we need to reduce the unequal burden of pain and improve the quality of pain care for all’.[[7]](#footnote-7)

The use of visual methodologies in qualitative research design is increasing[[8]](#footnote-8) as is the use of photo elicitation to promote healing from trauma. Images are an innovative and valuable means of triggering pain narratives, and art, in particular photography, a means of sharing and reflecting on experience. ‘Narrative medicine practices have coalesced from the intersection of literary studies, creative writing, disability studies, and narrative ethics with the health-care disciplines of nursing, social work, and medicine. The resultant practices are more able to elicit and work with stories of illness and fractured life worlds than they could in the past, and acknowledge the role of expressive storytelling and story-listening in medicine as forms of exploration, assimilation, and communication that promise better understanding and improvement of health care.’[[9]](#footnote-9)

When it seems there is no available language to communicate, to describe experience, people resort to metaphor.[[10]](#footnote-10) Metaphors are crucial to how we understand and communicate with each other.[[11]](#footnote-11) Visual metaphors add sensation to verbal language reminding us that, though processed in the brain, pain is experienced via the body, resonating in the space between those living with and those witnessing pain. Consultant paediatrician, Bozhena Zoritch, argues that medical and non-medical models have locked horns for too long and that we need ‘methods of entanglement, cohesion and collaboration.’[[12]](#footnote-12) Negotiation across the photographic surface allows for entanglement and collaboration to take place, facilitating the piecing together of fragmented lives in a reciprocal relationship of care while democratising the pain encounter.

***Face2face* and the space between word and image**

The *face2face* project at University College Hospital[[13]](#footnote-13) set out to address pain’s incommunicability and explore whether photographic images co-created with pain patients could provide an alternative language for the communication of pain. It became apparent that the images were not providing an alternative language as originally envisaged but re-invigorating existing language, initiating a symbiotic relationship between words and images capable of generating new language.

The seed of this idea dates back to *perceptions of pain* in 2001,[[14]](#footnote-14) a collaboration between myself and pain specialist Dr. Charles Pither, then medical director of INPUT pain Management Unit, St Thomas’ Hospital.In 2003 and 2004 the images created during *perceptions of pain* were exhibited widely, piloted in clinics across the UK and published in a book alongside essays and patient testimonies.[[15]](#footnote-15) Feedback from this showed a demand for the images to be more widely available and suggested further in-depth research was warranted.

In 2008 I began collaborating with facial pain specialist Professor Joanna Zakrzewska developing the *face2face* project with facial pain patients and clinicians from UCH. Facial pain has all the difficulties associated with musculoskeletal pain as well as additional challenges associated with the role of the face in communicating and social functioning. We were still researching whether and how photographic images of pain co-created with pain sufferers could help them communicate their pain to treating clinicians, and whether images could expand the dialogue around pain in the consulting room and thus improve mutual understanding. The difference to the earlier work was that this time I worked longitudinally with patients before, during, and after treatment or management developing a series of images representing different levels of pain, reflecting and feeding into changes patients had made in their perception of their pain.

A central/core/key aspect to all of these projects was the collaboration with pain sufferers to produce photographic images of their pain. These were negotiated differently with every participant, but what was essential was that they were *co-created* so as not to re-appropriate someone else’s experience of pain, which can happen all too easily along the diagnostic corridors of the hospital. Control of the lens confers power over how an illness is seen and understood by others, as photographer and activist Jo Spence demonstrated so powerfully with her own illness.[[16]](#footnote-16) By the time pain patients have arrived at a specialist centre they will almost inevitably have been on the passive receiving end of countless medical imaging processes. Participating in the co-creation of photographic images returns agency; I would suggest that the process can only be beneficial when sufferers have agency within it.

**Co-creative process during *face2face***

The sessions were held individually, mostly in rooms booked in the hospital but occasionally at other locations, significant for and selected byparticipants, such as derelict buildings in east London or in a participants’ garden in West Hampstead. The sessions were audio-recorded. The aim was to co-create photographic images which, as closely as possible, represented the pain sufferers’ unique experience of pain. The sessions (numbering between nine and twelve) happened at three points during the treatment journey: before, during and after management/treatment in order to prevent sufferers from being trapped not just within their pain but also within a single negative image. This meant each person worked with me for between six months and a year. The arc of time allowed changes sufferers had made in their perception of pain to be represented along with a sense of movement and transformation, where present, and produced a collection of images reflecting a broad range of intensities and pain qualities. Changes were always guided by the pain sufferer and no attempt was made to direct the process into reflecting a ‘positive’ journey.

Sessions usually began with questions about how the participant’s pain might be visualised: were there any metaphors they already had for it, or could it be reflected through particular materials, colours, light (or absence of light), or significant objects? All participants were asked to bring an object to the first session, which they felt represented an aspect of their experience of pain. Frequently used as metaphors for pain, the objects shifted the discussion towards personal rather than collective meaning and provided a starting point for the photographic process. The photographs were taken by me, using a high-resolution digital camera, and always in consultation with the sufferer. These would later be uploaded onto a computer and reviewed in subsequent sessions.. A selection of those photographs deemed to be ‘successful’ (as photographic) representations and close to the sufferer’s experience were made by myself and the patient together. These would then be modified following the session and sometimes printed or stitched onto or collaged with by the sufferer. Sometimes the photograph would be re-taken during the next session and refined when what the sufferer wanted the image to communicate became more evident.. The process brings into focus the importance of constructive dialogue between artist and sufferer and the role the artist plays as an active participant in the construction and reflection of narrative. It highlights ways in which narrative emerges through the communicative process .

**~~Why use Photography?~~**

There is a dark room. A shutter opens. The room is flooded with light that threatens to bleach the interior white.... Across the darkness, the fall of light is thus graphed by the grid built into the window of the converging lens and the geometry of the walls whose rectangulate architecture orchestrates the relation of the central opening to the focal plane and to the frame marked by the boundaries of that plane’s flat surface. This carefully constructed room has an old name. It is a camera.[[17]](#footnote-17)

Here, theorist John Tagg employs the metaphor of the house for the camera, a meeting point of exterior light and interior darkness into which it penetrates and onto whose walls it leaves traces of events beyond itself. This is a useful metaphor with which to begin exploring the specificities of photography that make it a particularly apposite medium for projects visualising pain and the subjective experience of others. It is also a useful metaphor through which to view pain as Sontag demonstrates (discussed later).

**Camera/House**

The house, a contained space where light enters through constructed apertures, is comparable to the interior of the body bounding the self, entered only via its natural orifices or those artificially constructed by medicine or injury. The house opens out as a metaphor for the psychological space of the mind or the photographic frame delineating and capturing one perspective, one moment in flux continuing beyond and external to its frame. To have visibility within a psychological space or within the physical space of the body, to produce a photograph at all, there has to be light, a space through which it travels and a surface onto which that light falls, resulting in exchange or ‘alchemy’. Tagg goes on to define the room as training light,

‘graphing it - quite literally, photo-graphing, subjecting light to the punctual rule of the room’s inbuilt geometrical law. The camera is, then, a place to isolate and discipline light, like a room in Jeremy Bentham’s Panopticon.’ [[18]](#footnote-18)

Like that room in the Panopticon, ‘the cell of the camera has its utility both as a training machine and as a device for producing and preserving text*.*’[[19]](#footnote-19) Here photography is associated not with a safe space, but with one of surveillance. This single metaphor brings together photography’s dual functions as both containing space, orchestrating a meeting between light and darkness, offering a membrane between internal and external worlds ,and its more dangerous function as a space of surveillance. Both of these intrinsic qualities of photography underline the importance of involving the subjects themselves in the representation of their experience, in order not to objectify their experience.

‘The pain is a house, with many rooms. Or, he is a house in which the pain lives. Or, they both live in the house together.’[[20]](#footnote-20)

In this quote from ‘*Man with a pain’* Susan Sontag uses the metaphor of the house to represent pain. Pain is depicted as a contained or containing space, a privatel, defended space, that is difficult for the external world to enter. ~~It is perhaps~~ This meeting point of dark and light, of internal and external ~~which~~ is as pivotal to pain as it is to photography and it is at this intersect that our work with images and pain ~~unknowingly~~ rests. In examining the spaces between word and image, the perspectives of clinician and patient, medicine and art, are we also exploring the function of liminal space, and questioning what role images can play in helping us understand or navigate it?

**~~The wound as liminal~~**

In terms of the body, a visible lesion or wound might be seen as a significant liminal site for the meeting of interior and exterior worlds, of what is visible and what is normally invisible. Petra Kuppers, describes the wound or scar as:

a locus of memory, of bodily change. Like skin, a scar mediates between the outside and the inside, but it also materially produces, changes, and overwrites its site.[[21]](#footnote-21)

The photograph could also be conceived of as a wound, or as its consequence, the scar. A wound punctures what we expect to see – punctures the safe boundaries of self and other – and draws upon individual association and cultural memory, signifying beyond its self. Roland Barthes captures this beautifully in his conception of the photograph as a wound ~~and his description of the~~ *~~punctum~~*. when he writes:

‘I wanted to explore it not as a question (a theme) but as a wound: I see, I feel, hence I notice, I observe, and I think.’[[22]](#footnote-22)

Barthes identifies the ability of photographs to reflect beyond the limits of their frame, to look beneath what is apparent. The photograph is not an exact ‘copy’ or a literal ‘representation’; it is a construct, it has an author, it involves selection and framing. Thus Barthes moves away from his initial position that a photograph simply *denotes*, towards accepting that it can also *connote*. He describes this as the ‘*punctum*’ in a photograph. Further drawing on the metaphor of the wound, this punctum is the element that is able to elicit affect:

A Latin word exists to designate this wound, this prick, this mark made by a pointed instrument: … This second element which will disturb the studium I shall therefore call punctum; for punctum is also: sting, speck, cut, little hole – and also a cast of the dice. A photograph’s punctum is that accident which pricks me (but also bruises me, is poignant to me).[[23]](#footnote-23)

Barthes continues to emphasise the *punctum* as a detail:

‘in order to perceive the *punctum*, no analysis would be of any use to me … it suffices that the image be large enough, that I do not have to study it (this would not help at all), that, given right there on the page, I should receive it right here in my eyes. [[24]](#footnote-24)

This last notion of ‘receiving’ the image ‘right here in my eyes’ is a striking parallel to Marshall and Bleakley’s argument that clinicians should ‘receive’ rather than ‘take’ a history.[[25]](#footnote-25)

~~In his analysis of Barthes’ notion of the~~ *~~punctum~~*~~, Fried identifies how~~ Barthes saw the *punctum* not as a result of the photographer’s intention; but dependent instead on its impact on the viewer. In other words, the *punctum* ‘pricks’ because of the relationship between the *photograph* and the viewer, ~~not because the photographer has shown something to the viewer~~.[[26]](#footnote-26)

In the photographs produced during *face2face* the ‘*punctum*’ is not always accidental and has not been solely achieved as a result of the relationship between the image and the viewer. On the contrary, it has ~~often~~ emerged from a lengthy process and out of complex exchanges between myself and the person with pain. Nevertheless, those elements which ‘prick’ or elicit deeper psychological meaning for the patient are frequently only recognised when viewing the final photograph. One participant remarked:

I didn’t realise until I saw the photograph but it is about having the inner and the outer experience at the same time. It is because you have inserted the collage between my face and my hand. It is about touch.’

Another patient observed:

Seeing the photograph made me realise what I had done to myself.

The challenge in representing chronic pain is that the wounds felt ~~represented~~ are seldom visible and often not even tangible. This is why giving them form, making them tangible, sharable and visible to others becomes central. It is also important to remember that photographs do not just allow us to recollect personal experience or to elicit personal narrative - they also create it. Where Tagg suggests that the production of images ‘animates’ rather than discovers meaning,[[27]](#footnote-27) I believe it both discovers and animates. Meaning is at once constructed and revealed during the co-creation process. This is another reason why it is vital that pain sufferers play an active role in both creation and interpretation.

During the research process a series of co-created images was publicly exhibited (figs 1 – 5) . Visitors were invited to respond to the photographs and to leave their written interpretation as well as a description of their own occupation. It was a series in which a pain sufferer attempted to give visual form to her pain through the concept of a *shadow sandwich*. It was the shadow element in this series of images that most people responded to, suggesting its significance. Their interpretation seemed to be influenced directly by the discipline in which they worked, echoing the different agendas present in the consulting room,[[28]](#footnote-28) which influence the clinical encounter. I was interested in how the polysemy of the photographs facilitated a multiplicity of interpretations and when and how these interpretations intersected or conflicted with those of the sufferer. The subjectivity of interpretation parallels the subjectivity of pain. Like pain, it resonates in relation to the past as well as the present. Evidencing the different ways in which individuals construct meaning through images thus provides a glimpse into the (various) ways in which significance and meaning are conferred on pain experience. The process demonstrates the need for a flexible and negotiated dialogue capable of interweaving multiple interpretations. Your ‘shadow’ is not the same as my ‘shadow’, just as my ‘pain’ is not the same as your ‘pain’. Images make this explicit.

**Multiple interpretations: multiple voices / Pain as a shadow**

A shadow is by definition indistinct, poorly delineated and transient. In language, ‘shadow’ is often used metaphorically to suggest diminished abilities, power, strength or beauty, as in ‘a shadow of his/her former self’. The shadows in the picture (figs 3 – 4) suggest that the pain reduces the sufferer to something weaker, less individual, less active, more anonymous than they would otherwise be; that other people may not be able to see them and value them as they otherwise might; that the sufferer’s own self-image is that of someone who is less than a full, complete individual … The absence of colour and perspective reinforces my impression of a diminished existence. (Linguist)

This description by the linguist viewing the photographs, is very close to the sufferer’s own testimony:

‘It’s just a way of explaining that you really don’t feel like the person you were at all… there’s almost no relationship, there’s such an emptiness inside of you cause you just feel completely burned, like there’s an empty shell’

The series of images (figs 1 -5) reveals significant aspects of chronic pain experience: the loss of identity, the multifarious impact of loss, and the existence of related shadows. It is worth noting that the shadow isn’t necessarily always negative. Carl Gustav Jung, for instance, defined the shadow as the personification of particular aspects of the unconscious personality. If the shadow represents the unlived and repressed side of the ego, giving the shadow form could be a positive thing. Jung, however, also claims this interpretation is a misunderstanding and that “the shadow is simply the whole unconscious.”[[29]](#footnote-29)

A radiologist, psychotherapist, artist, clinician, writer, social worker and architect also interpreted the shadow in different ways, but they all identified the shadow metaphor as central to the image’s construction of meaning; and each time their professions influenced their readings of the image.

I see the images in terms of the relationship between you (Deborah) and the patient as well as the journey of her treatment. … In the first image she is just a shadowy figure as she has not yet revealed herself to you. In the second image she appears as a patient – the bread on the examining couch. In the third image it seems to me that she has revealed a lot about the nature of her pain – she is the pain in a sense in the form of the mouldy bread… (Psychotherapist)

The first image is of a faint shadow – a silhouette of a child or girl’s head cast onto a wall showing hands raised in a manner that seems placating, defensive or beseeching. This is haunting and insubstantial. … It suggests the soul within, rather than the substantive body. Its posture suggests that the soul is not at ease but it is difficult to tell clearly what the source of their anxiety is. (Radiologist)

Lost, confrontational. Consumed by shadow. Again I sense the distancing created by pain. The shadow gestures differ from each other. Confusion. Feeling separated from body/self. (Artist)

The shadow – she is almost there, almost not there. … The shadow ever sent from stone, from bread, sinking into matter … The gesture in shadow, the blurred disappearing form with formlessness, concentric circles of rain on water, and the eye travels upwards looking for her. (Writer)

Is the shadow malevolent? Ambiguous, feels as though she is subjected to something … I see a circle rather than a line, returning. (Artist and Psychotherapist)

Pain is a powerful emotion and if present on the face it is so much more devastating. It results in loss of identity, the patent feels that her own life has gone and pain has now taken over her identity. The patient has now come to seek help from a health care professional and is hoping that they will be able to make sense of what has happened to her. (Clinician)

The image is a representation of how the patient sees herself and also how she feels others perceive her. … The shadow is of a woman of black Afro/Caribbean descent who portrays herself as this shadow due to a possible lack of identity. … Racial differences are often misunderstood and misdiagnosed by health care professionals and language can also be a possible barrier … (Social Worker)

The portrait is absent, it is spacialised through shadow … Are these the hands of the artist, of the doctor, of the patient, I cannot tell, all subjects converge … (Architect)

**Membrane and meaning**

The number of interpretations arrived at for one aspect of one image reveals the multiplicity of potential meanings of all the photographs. The space between meanings could be visualised as a membrane through which exchange needs to flow both ways in order to arrive at a deeper mutual understanding. Accepting that we do not all see an image in the same way forces us to negotiate. If language becomes negotiated in response to the images, can it remain negotiated in response to pain, and in a clinical context can it feed into a negotiated dialogue during the rest of the consultation? Napier et al[[30]](#footnote-30) argue that ideas about health vary widely across cultures and should not be merely defined by measures of clinical care and disease. This applies even more to beliefs around pain, which are not only culturally constructed but also intensely personal. Can the significance of each individual’s experience of pain be revealed through discussing the images? Is the next step in this research journey the development of a cross-cultural iconography for pain, co-creating images with people from a range of cultures learning from a variety of personal and collective frameworks for pain? Funding permitting, this suggests itself as a fruitful future route.

What is worth noting is that in the interpretations above the shadow is frequently linked to notions of ambiguity and to a lack of resolution. These images do not depict pain as resolved, they depict pain alternating and spiralling around the same issues in a continuum. If pain were conceived of as a material, as artist Johanna Willenfelt proposes,[[31]](#footnote-31) would that material in fact be a shadow?

Photographs, with their ambiguity and polysemy, open up avenues of communication that might otherwise have remained closed. The images aim to elicit a sharing of knowledge; to expose what an individual patient *is* experiencing, and not what they *should* be experiencing, albeit in the hope that transformation is possible through dialogue. Through analysing these images my belief is growing that they reflect an emotional journey of direct relevance to pain perception and experience.

**Conclusion**

We know the photograph is a construct resulting from processes of selection, creation and re-presentation, yet in our minds it is still aligned with notions of documentation and authenticity. It is thus a perfect medium for validating the processes of the life of another, which make up their subjective reality. Photography is more than a medium; it is a way of making known, a process of shaping experience. As social psychologist Alan Radley writes, photographs gain their meaning from the acts that produce them.[[32]](#footnote-32)

I have only touched lightly on notions of ownership through the involvement of the subject in the creation of the photograph. When the images are used as a resource in the clinical setting with new patients, those being asked to select from this bank of images (to take into their consultation and use as springboards for dialogue) have not been directly involved in making them, but have nevertheless been involved in acts of ownership through selection of the images.[[33]](#footnote-33) For me this highlights the sometimes invisible and apparently insignificant acts, which make up a negotiated duel over ownership of illness experience and its language, over the body and its texts, which we should pay more attention to. Images serve to surpasses those dynamics of a *duel* simultaneously highilighting and mitigating them.

Barbara Stafford has written extensively on the art object in relation to analogy? and visual metaphor as means’ of understanding the human body in the context of neuroscience and consciousness theory.[[34]](#footnote-34) She emphasises the instinctual as opposed to logical nature of the leap which the visual metaphor makes from the known to the unknown, claiming that ‘the body cannot be “read”, it is “perceived, visually, sensually.”’ Could not the same be said of the photograph, which stands in as a visual metaphor for the body in pain? We do not just ‘read’ it; we perceive it visually and sensually. If we only ‘read’ it, we omit the most insistent aspect of the pain experience itself - that it is experienced with and through the body. Its representation demands a material and corporeal element. It cannot be communicated via language alone.

Elizabeth Grosz provides a re-definition of subjectivity which we could use to approach pain and the image.[[35]](#footnote-35) She theorises the body as part of the construct of subjectivity rather than something affected by it. In a similar way, the photograph acts as a physical object while signifying subjective experience. The image has been projected onto a surface that during the co-creation process may have been torn, etched or stitched into in a way that parallels how narrative and experience are etched into our bodies. Can such a corporeal conception of subjectivity bring us closer to the lived experience of pain, removing the need for distinction between psychological and physical suffering?

In his programme notes to Stockhausen’s *Carre* (Square), composer Jonty Harrison writes:

Black and white are normally seen as opposites and, thus, mutually exclusive. However, says Stockhausen, by creating between them a scale of various shades of grey and then reordering the scale into a series, we effectively draw the apparent opposites of black and white into a higher unity – not black as the opposite of white, but black as a degree of white.[[36]](#footnote-36)

Could a visual language help create a similar scale for pain which allows shifts in perception necessary to accommodate both somatic and affective elements within one definition, framing them not as opposites but as degrees of each other? Could this bring us closer to a re-definition of pain which includes both physical and emotional pain that many, including physician and academic David Biro, argue for?[[37]](#footnote-37) Can photographs help bring pain out of the shadows and into the light of our shared humanity? Can images transform space into a membranous material within which the possibility of meaningful two-way exchange is enhanced, supporting my long held hope for fluid two-way exchange to become normal practice within medical dialogue?

Come with me; for my painful wound

Requires thy friendly hand to help me onward

Sophocles, Philoctetes

**NOTES:**

1 Susan Sontag (2003) *Regarding the pain of others*. London: Hamish Hamilton.

2 See Elaine Scarry (1985) *The body in pain: the making and unmaking of the world*. Oxford: Oxford University Press.

3 Petra Kuppers (2007) *The scar of visibility: Medical performances and contemporary art.* Minnneapolis:University of Minnesota Press: 76

4 Barbara Marie Stafford (2007) *Echo Objects: The Cognitive Work of Images* Chicago, London: The University of Chicago Press: 126 (Referencing Leibniz)

5 Elaine Scarry (1985) *The body in pain: the making and unmaking of the world*. Oxford: Oxford University Press: 5

6 See Arthur Kleinman (1988) *The illness narratives, suffering, healing & the human condition*. USA: Basic Books. Arthur Kleinman (2008) Catastrophe and caregiving: the failure of medicine as an art’, *Lancet* (371): 22–23; Arthur Kleinman (2015) Care: in search of a health agenda.

7 Carmen R Green (2011) Being present: the role of narrative medicine in reducing the unequal burden of pain. *Pain* (152): 965-966.

8 See Paula Reavey (2012) *Visual methods in psychology: Using and interpreting images in qualitative research*. Routledge. Also Isabella E Nizza, Jonathan Smith and Jamie Kirkham (2017). ‘Put the illness in a box’: a longitudinal interpretative phenomenological analysis of changes in a sufferer’s pictorial representations of pain following participation in a pain management programme. *British Journal of Pain*, 2049463717738804 (temp citation as not yet assigned to an issue).

9 Brian Hurwitz and Rita Charon (2013) A Narrative future for healthcare. *Lancet.* (381): 1886-1887

10 See David Biro (2010) *The language of pain. Finding words, compassion and relief*. New York: WW Norton & Co. Also, David Biro (2014) ‘Psychological Pain: Metaphor or Reality?’ In: Boddice R. (ed.) *Pain and Emotion in Modern History*. Basingstoke: Palgrave Macmillan:53 – 65.

11 George Lakoff and Mark Johnson (1980) *Metaphors we live by*. Chicago: University of Chicago Press

12 Bozhena Zoritch (2017) *Entangled story of Attachment Deficit Hyperactivity Disorder (ADHD).* Paper presentation. Association of Medical Humanities Conference, Keele Univeristy.

13 The project had several strands: art workshops for clinicians and patients to attend together; the co-creation of photographs with facial pain patients before during and after treatment making visible and re-enforcing changes patients had made in perception of their pain; the creation of an image resource integrating photographs from both *Perceptions of Pain* and *Face2face* as an innovative communication tool for clinical use; piloting the image resource as a pack of 54 PAIN CARDS in pain consultations (See Deborah Padfield et al (2015) Do photographic images of pain improve communication during pain consultations? *Pain Research & Management*. 20(3) :123 – 128) and an artist’s film focusing on doctor-patient dialogue and the role of narrative, positively reviewed in the medical and general press (Jones D (2011) Portraits of Pain. *Lancet*, 378, (9789) 30 (July): 391). Also Padfield D, Chadwick T and Omand H (2017) The body as image: image as body. *Lancet* 389 (10076): 1290–1291 and Semino E, Zakrzewska JM and Williams C de C A (2017) Images and the dynamics of pain consultations. *Lancet*, 2017; 389(10075):1186-1187.

For more information please see:

<http://www.ucl.ac.uk/slade/research/mphil-phd/deborah-padfield>

and <http://www.ucl.ac.uk/slade/research/projects/pain-speaking-the-threshold>

14 Perceptions of Pain was a collaboration between myself and Dr Charles Pither with staff and patients from INPUT Unit, St Thomas’ Hospital, London where I worked individually with pain sufferers once a week on the four week residential pain management programme to co-create photographic images which reflected their experience of pain. For more information please see Padfield 2003, Padfield et al. 2010 and Padfield 2011.

15 Deborah Padfield (2003) *Perceptions of Pain*, 1st edition. Stockport: Dewi Lewis Publishing.

16 Jo Spence (1986) *Putting Myself in the Picture*. London: Camden Press.

Up to page 4 and the co-creative process section – next ref appears to be on page 5

17 John Tagg (2009) *The Disciplinary Frame: Photographic Truths and the Capture of Meaning*. Minneapolis: University of Minnesota Press: 1

18 Ibid.

19 Ibid.

20 Susan Sontag (1964) Man with a Pain. *Harper’s Magazine* (April): 73

21 Kuppers, *The scar of visibility: Medical performances and contemporary art*: 1

22 Roland Barthes (1980) *Camera Lucida: Reflections on Photography.* London: Vintage: 21

23 Ibid: 26-27

24 ibid: 42-43

25 Robert Marshall and Alan Bleakley (2013) ‘Lost in translation. Homer in English; the patient’s story in medicine’ *Med Humanit (*39): 47-52

26 Michael Fried (2012) *Why Photography Matters as Art as Never before*. New Haven ; London: Yale University Press: 103 -104

27 John Tagg (1980) Power and Photography: Part One, A Means of Surveillance: The Photograph as Evidence in Law. *Screen Education.* (36): 17–55

28 Diane Kenny (2004) Constructions of chronic pain in doctor-patient relationships: bridging the communication chasm. *Patient Education and Counseling* 52(3): 297–305

29 Marie-Louise von Franz (1974) *Shadow and Evil in Fairytales, Zurich*. Spring Publication for The Analytical Psychology Club of New York : 5

30 David Napier et al (2014) Culture and Health. *Lancet* (384): 1607

31 Johanna Willenfelt (2014) Documenting Bodies: Pain Surfaces. Boddice R (ed) *Pain and Emotion in Modern History*. Basingstoke and New York: Palgrave Macmillan: 260 – 276

32 Alan Radley (2010) What people do with pictures. *Visual Studies*, 25 (3): 268 - 279

33 For detailed methodology please see Deborah Padfield et al (2015) Do photographic images of pain improve communication during pain consultations? *Pain Research & Management*, 20(3): 123 – 128 and Claire Ashton James et al. ‘Can images of pain enhance patient–clinician rapport in pain consultations?’ *British Journal of Pain*, 2017;11(3): 144-152.

DOI: <https://doi.org/10.1177/2049463717717125>

34 See Barbara Marie Stafford (1993) *Body Criticism, Imaging the Unseen in Enlightenment Art and Medicine*. Cambridge Massachusetts: MIT Press; Stafford (1999) *Visual Analogy: consciousness as the art of connecting.* Massachusetts. London: MIT Press; and Stafford (2007) *Echo Objects*.

35 See Elizabeth Grosz (1994) *Volatile Bodies, Toward a corporeal feminism* .Indiana: Indiana University Press.

36 Karlheinz Stockhausen (2010) quoted in Jonty Harrison (ed.) Programme Notes, Birmingham.

37 David Biro (2014) ‘Psychological Pain: Metaphor or Reality?’ In: Boddice R. (ed.) *Pain and Emotion in Modern History*. Basingstoke: Palgrave Macmillan:53 – 65

**REFERENCES:**

Ashton–James C, Dekker P, Addai-Davis J, Chadwick T, Zakrzewska JM, Padfield D, Williams A C de C (2017) Can images of pain enhance patient–clinician rapport in pain consultations? *British Journal of Pain*. 1-9

Barthes R. (1980) *Camera Lucida: Reflections on Photography.* (1993) R.Howard (trans.) London: Vintage

Biro D. (2010) *The language of pain. Finding words, compassion and relief*. New York: WW Norton & Co.

Biro D. (2014 ) ‘Psychological Pain: Metaphor or Reality?’ In: Boddice R. ed. *Pain and Emotion in Modern History*. Basingstoke: Palgrave Macmillan: 53 – 65.

Fried M. (2012) *Why Photography Matters as Art as Never before*. New Haven ; London: Yale University Press: 103 -104

Green C.R. (2011) Being present: the role of narrative medicine in reducing the unequal burden of pain. *Pain* (152): 965-966

Grosz E. (1994) *Volatile Bodies: Toward a corporeal feminism*. Indiana: Indiana University Press.

Hurwitz B, Charon R. (2013) A Narrative future for healthcare. *Lancet.* (381): 1886-1887

Jones D. (2011) Portraits of Pain. *Lancet*. 378 (9789) July 30: 391

Kenny D. (2004) Constructions of chronic pain in doctor-patient relationships: bridging the communication chasm. *Patient Education and Counseling* 52(3): 297–305

Kimberlin C. Brushwood D, Allen W, Radson E and Wilson D. (2004) Cancer patient and caregiver experiences: communication and pain management issues. *Journal of Pain and Symptom Management*. (28): 566–78

Kleinman A. (1988) *The illness narratives, suffering, healing & the human condition*. USA: Basic Books

Kleinman A. (2008) Catastrophe and caregiving: the failure of medicine as an art. *Lancet.*(371): 22–23.

Kleinman A. (2015) Care: in search of a health agenda. *Lancet*. (386): 240-241

Kuppers, P. (2007) *The scar of visibility: Medical performances and contemporary art.* Minnneapolis:University of Minnesota Press

Lakoff G, Johnson M. (1980) *Metaphors we live by*. Chicago, London: University of Chicago Press

Marshall R. and Bleakley A. (2013) ‘Lost in translation. Homer in English; the patient’s story in medicine’ *Med Humanit (*39): 47-52

Napier D et al (2014) Culture and Health. *Lancet* (384): 1607

Nizza, I. E., Smith, J. A., & Kirkham, J. A. (2017). ‘Put the illness in a box’: a longitudinal interpretative phenomenological analysis of changes in a sufferer’s pictorial representations of pain following participation in a pain management programme. British Journal of Pain, 2049463717738804

Padfield D. (2003) *Perceptions of Pain* (1st edition) Stockport: Dewi Lewis Publishing

Padfield et al. (2010) A slippery surface, can photographic images of pain improve communication in pain consultations? *International Journal of Surgery*, 8 (2) :144–150

Padfield D (2011) Representing the pain of others. *Health*. 15, (3): 241–257

Padfield D, Zakrzewska J M, Williams A C deC (2015). Do photographic images of pain improve communication during pain consultations? *Pain Research & Management*. 20 (3): 123 – 128

Padfield D, Chadwick T, Omand H (2017) The body as image: image as body. *Lancet*: (389) 10076: 1290–1291

Radley A (2010) What people do with pictures. *Visual Studies*. 25 (3): 268 — 279

Reavey P (2012) *Visual methods in psychology: Using and interpreting images in qualitative research*. Routledge.

Scarry E (1985) *The body in pain: the making and unmaking of the world*. Oxford: Oxford University Press.

Semino E, Zakrzewska JM, Williams A C de C (2017) Images and the dynamics of pain consultations The Lancet 2017; Vol 389 (10075):1186-1187

Sontag S (1964) Man with a Pain. *Harper’s Magazine*. April: 72-75

Sontag S (2003) *Regarding the pain of others*. London: Hamish Hamilton.

Sophocles (409 BC) Philoctetes.

Spence J (1986) *Putting Myself in the Picture*. London: Camden Press

Stafford B (1993) *Body Criticism, Imaging the Unseen in Enlightenment Art and Medicine*. Cambridge Massachusetts: MIT Press

Stafford B (1999) *Visual Analogy: consciousness as the art of connecting*, Massachusetts. London: MIT Press

Stafford B (2007) *Echo Objects, The Cognitive Work of Images*. Chicago, London: The University of Chicago Press

Stockhausen K (2010) in Harrison J ed. Programme Notes. Birmingham

Tagg, J (1980) Power and Photography: Part One, A Means of Surveillance: The Photograph as Evidence in Law. *Screen Education* (36): 17–55

Tagg J (2009) *The Disciplinary Frame: Photographic Truths and the Capture of Meaning*. Minneapolis: University of Minnesota Press.

Von Franz ML (1974) *Shadow and Evil in Fairytales, Zurich*. Spring Publication for The Analytical Psychology Club of New York.

Willenfelt J (2014) Documenting Bodies: Pain Surfaces. Boddice R (ed.) *Pain and Emotion in Modern History*. Basingstoke and New York: Palgrave Macmillan: 260 – 276

Williams AC de C, Craig K.D (2016) Updating the definition of pain. *Pain* 157: 2420–2423

Yates PM, Edwards HE, Nash RE, et al. (2002) Barriers to effective cancer pain management: a survey of hospitalized cancer patients in Australia. *Journal of Pain and Symptom Management*. (23): 393–405

Zoritch B (2017) *Entangled story of Attachment Deficit Hyperactivity Disorder (ADHD).* Paper presentation. Association of Medical Humanities Conference, Keele Univeristy

**Legend for figures:**

Fig 1 Deborah Padfield with Linda Williams, untitled from the series *face2face*, 2008–2013, Digital Archival Print

© Deborah Padfield

Fig 2 Deborah Padfield with Linda Williams, untitled from the series *face2face*, 2008–2013, Digital Archival Print

© Deborah Padfield

Fig 3 Deborah Padfield with Linda Williams, untitled from the series *face2face*, 2008–2013, Digital Archival Print

© Deborah Padfield

Fig 4 Deborah Padfield with Linda Williams, untitled from the series *face2face*, 2008–2013, Digital Archival Print

© Deborah Padfield

Fig 5 Deborah Padfield with Linda Williams, untitled from the series *face2face*, 2008–2013, Digital Archival Print

© Deborah Padfield

1. Susan Sontag (2003) *Regarding the pain of others*. London: Hamish Hamilton. [↑](#footnote-ref-1)
2. See Elaine Scarry (1985) *The body in pain: the making and unmaking of the world*. Oxford: Oxford University Press. [↑](#footnote-ref-2)
3. Petra Kuppers (2007) *The scar of visibility: Medical performances and contemporary art.* Minnneapolis:University of Minnesota Press: 76. [↑](#footnote-ref-3)
4. Barbara Marie Stafford (2007) *Echo Objects: The Cognitive Work of Images* Chicago, London: The University of Chicago Press: 126 (Referencing Leibniz). [↑](#footnote-ref-4)
5. Scarry, *The body in pain:* 5. [↑](#footnote-ref-5)
6. See Arthur Kleinman (1988) *The illness narratives, suffering, healing & the human condition*. USA: Basic Books. Arthur Kleinman (2008) Catastrophe and caregiving: the failure of medicine as an art’, *Lancet* (371): 22–23; Arthur Kleinman (2015) Care: in search of a health agenda. [↑](#footnote-ref-6)
7. Carmen R Green (2011) Being present: the role of narrative medicine in reducing the unequal burden of pain. *Pain* (152): 965-966. [↑](#footnote-ref-7)
8. See Paula Reavey (2012) *Visual methods in psychology: Using and interpreting images in qualitative research*. Routledge. Also Isabella E Nizza, Jonathan Smith and Jamie Kirkham (2017). ‘Put the illness in a box’: a longitudinal interpretative phenomenological analysis of changes in a sufferer’s pictorial representations of pain following participation in a pain management programme. *British Journal of Pain*, 2049463717738804 (temp citation as not yet assigned to an issue). [↑](#footnote-ref-8)
9. Brian Hurwitz and Rita Charon (2013) A Narrative future for healthcare. *Lancet.* (381): 1886-1887. [↑](#footnote-ref-9)
10. See David Biro (2010) *The language of pain. Finding words, compassion and relief*. New York: WW Norton & Co. Also, David Biro (2014) ‘Psychological Pain: Metaphor or Reality?’ In: Boddice R. (ed.) *Pain and Emotion in Modern History*. Basingstoke: Palgrave Macmillan: 53 – 65. [↑](#footnote-ref-10)
11. George Lakoff and Mark Johnson (1980) *Metaphors we live by*. Chicago: University of Chicago Press. [↑](#footnote-ref-11)
12. Bozhena Zoritch (2017) *Entangled story of Attachment Deficit Hyperactivity Disorder (ADHD).* Paper presentation. Association of Medical Humanities Conference, Keele Univeristy. [↑](#footnote-ref-12)
13. The project had several strands: art workshops for clinicians and patients to attend together; the co-creation of photographs with facial pain patients before during and after treatment; an artist’s film, the creation of an image resource (54 pain cards/images of pain) integrating photographs from both *Perceptions of Pain* and *Face2face* as an innovative communication tool for clinical use, subsequently piloted by ten specicalists (See Deborah Padfield et al (2015) Do photographic images of pain improve communication during pain consultations? *Pain Research & Management*. 20(3) :123 – 128) Padfield D, Chadwick T and Omand H (2017) The body as image: image as body. *Lancet* 389 (10076): 1290–1291 and Semino E, Zakrzewska JM and Williams C de C A (2017) Images and the dynamics of pain consultations. *Lancet*, 2017; 389(10075):1186-1187.

    For more information please see:

    <http://www.ucl.ac.uk/slade/research/mphil-phd/deborah-padfield>

    and <http://www.ucl.ac.uk/slade/research/projects/pain-speaking-the-threshold> [↑](#footnote-ref-13)
14. Perceptions of Pain was a collaboration between myself and Dr Charles Pither with staff and patients from INPUT Unit, St Thomas’ Hospital, London where I worked individually with pain sufferers once a week on the four week residential pain management programme to co-create photographic images which reflected their experience of pain. For more information please see Padfield 2003, Padfield et al. 2010 and Padfield 2011 [↑](#footnote-ref-14)
15. Deborah Padfield (2003) *Perceptions of Pain*, 1st edition. Stockport: Dewi Lewis Publishing. [↑](#footnote-ref-15)
16. Jo Spence (1986) *Putting Myself in the Picture*. London: Camden Press. [↑](#footnote-ref-16)
17. John Tagg (2009) *The Disciplinary Frame: Photographic Truths and the Capture of Meaning*. Minneapolis: University of Minnesota Press: 1. [↑](#footnote-ref-17)
18. Ibid. [↑](#footnote-ref-18)
19. Ibid. [↑](#footnote-ref-19)
20. Susan Sontag (1964) Man with a Pain. *Harper’s Magazine* (April): 73. [↑](#footnote-ref-20)
21. Kuppers, *The scar of visibility: Medical performances and contemporary art*: 1. [↑](#footnote-ref-21)
22. Roland Barthes (1980) *Camera Lucida: Reflections on Photography.* London: Vintage: 21. [↑](#footnote-ref-22)
23. Ibid: 26-27. [↑](#footnote-ref-23)
24. ibid: 42-43. [↑](#footnote-ref-24)
25. Robert Marshall and Alan Bleakley (2013) ‘Lost in translation. Homer in English; the patient’s story in medicine’ *Med Humanit (*39): 47-52. [↑](#footnote-ref-25)
26. Michael Fried (2012) *Why Photography Matters as Art as Never before*. New Haven ; London: Yale University Press: 103 -104. [↑](#footnote-ref-26)
27. John Tagg (1980) Power and Photography: Part One, A Means of Surveillance: The Photograph as Evidence in Law. *Screen Education.* (36): 17–55. [↑](#footnote-ref-27)
28. Diane Kenny (2004) Constructions of chronic pain in doctor-patient relationships: bridging the communication chasm. *Patient Education and Counseling* 52(3): 297–30. [↑](#footnote-ref-28)
29. Marie-Louise von Franz (1974) *Shadow and Evil in Fairytales, Zurich*. Spring Publication for The Analytical Psychology Club of New York : 5. [↑](#footnote-ref-29)
30. David Napier et al (2014) Culture and Health. *Lancet* (384): 1607. [↑](#footnote-ref-30)
31. Johanna Willenfelt (2014) Documenting Bodies: Pain Surfaces. Boddice R (ed) *Pain and Emotion in Modern History*. Basingstoke and New York: Palgrave Macmillan: 260 – 276 [↑](#footnote-ref-31)
32. Alan Radley (2010) What people do with pictures. *Visual Studies*, 25 (3): 268 – 279. [↑](#footnote-ref-32)
33. For detailed methodology please see Deborah Padfield et al (2015) Do photographic images of pain improve communication during pain consultations? *Pain Research & Management*, 20(3): 123 – 128 and Claire Ashton James et al. ‘Can images of pain enhance patient–clinician rapport in pain consultations?’ *British Journal of Pain*, 2017;11(3): 144-152.

    DOI: <https://doi.org/10.1177/2049463717717125> [↑](#footnote-ref-33)
34. See Barbara Marie Stafford (1993) *Body Criticism, Imaging the Unseen in Enlightenment Art and Medicine*. Cambridge Massachusetts: MIT Press; Stafford (1999) *Visual Analogy: consciousness as the art of connecting.* Massachusetts. London: MIT Press; and Stafford (2007) *Echo Objects*. [↑](#footnote-ref-34)
35. See Elizabeth Grosz (1994) *Volatile Bodies, Toward a corporeal feminism* .Indiana: Indiana University Press. [↑](#footnote-ref-35)
36. Karlheinz Stockhausen (2010) quoted in Jonty Harrison (ed.) Programme Notes, Birmingham. [↑](#footnote-ref-36)
37. David Biro (2014) ‘Psychological Pain: Metaphor or Reality?’ In: Boddice R. (ed.) *Pain and Emotion in Modern History*. Basingstoke: Palgrave Macmillan: 53 – 65. [↑](#footnote-ref-37)