

Face2face: sharing the photograph within medical pain encounters; a means of democratization

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Abstract

Pain is common and difficult to communicate or reduce into the verbal or numerical scales commonly used in clinical practice. Some academics have argued that pain resists description in language while others have argued conversely that it generates language. This chapter identifies the limitations of verbal language and current standardized scores for assessing pain, highlighting the social and economic (as well as individual) costs of pain's incommunicability, so often resulting in inadequate treatment and increased suffering. It explores the specificities of the photographic medium demonstrating that visual images (in particular photographs) can be alternative vehicles for eliciting language and narrative capable of expanding and improving communication and clinician-patient interaction within medical pain consultations. Against the backdrop of other work exploring the value of arts and humanities to pain medicine, it focuses on a fine art/medical collaborative project, *face2face*, at a leading London teaching Hospital, which co-created images of pain with pain sufferers and piloted a selection of these in the clinics of ten experts. Giving examples of images from the project as patients progressed through their management, it also reports early research findings suggesting that the verbal language is enriched and the non-verbal interaction impacted on. It concludes that further investigation is necessary from multidisciplinary perspectives but that images and image-making processes should be considered valuable tools for enhancing and democratizing medical pain encounters.

DEBORAH PADFIELD & JOANNA M ZAKRZEWSKA

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THE CHALLENGE OF PAIN TO COMMUNICATION

Pain is common and difficult to communicate [1-3], or reduce into the verbal or numerical scales commonly used in clinical practice. Academics from Scarry [4] to Charon [5] have argued that pain resists description in language while Biro [6] and Bourke [7] have argued conversely that it generates language. This paper identifies the limitations of verbal language and current standardized scores for assessing pain arguing instead that visual images (in particular the photograph) can elicit language and narrative capable of expanding and improving communication and clinician-patient interaction specifically within medical pain consultations but with implications for use in other contexts.

The paper focuses on a collaborative photographic project between Fine Art and Medicine, *face2face*, [8- 10] at a leading London teaching hospital, itself building on an earlier sciart project, *perceptions of pain* [11-12]. Both projects sought to develop a visual as opposed to verbal language as an alternative vehicle for communicating and capturing pain. Contrary to expectation it became possible to hypothesise that the images' most powerful potential was not in replacing verbal language but in regenerating it, catalyzing new descriptors for pain from sufferers' own worlds (as opposed to the pre-prescribed words of the McGill Pain Questionnaire), and highlighting the most problematic aspects of their lived

experience. The method of using visual images as a communication aid [12] is proposed as a complement rather than alternative to existing measures, building on methods of photo-elicitation in the social sciences and the current growing interest in narrative medicine and the influence of the arts and humanities on medical practice. The study builds on calls for the democratization of medicine arguing the '*humanities educate for democratic habits and ... medicine is in need of democratization, bearing a historical legacy of authority-led structures and hierarchical teamwork*' [13].

Redefining chronic pain

American physician and academic, David Biro argues for a redefinition of pain to one which makes no distinction between emotional and physical pain [14]. In this context images are useful for collapsing both within a single image. The photograph's ability to signify multiple meanings refutes reductionist readings along Cartesian binaries, opening up discussions around interpretation, significance and meaning. Biro proposes the IASP's definition be expanded to include '*the aversive feeling of injury to one's person and the threat of further potentially more serious injury. It can be described metaphorically*' [15]. He argues this would reduce semantic confusion around pain, and provide a better framework for managing patients, encouraging new ways of treating them by removing a distinction between actual and perceived damage, between physical and emotional pain. Patients' perception of their pain and the narrative into which they fit it thereby becomes central to discussion of pain [2]. Images can be a way of revealing this framework and the significance of pain experience for an individual. Bourke [7,16] argues that pain is experienced culturally and socially. Images may be a powerful tool for eliciting the

context in which pain is experienced by an individual and unraveling its meaning with them.

With no biomarkers, pain remains a subjective sensation relying on the patient's story, and on the sufferer being able to express it [17]. As Boddice argues, those with pain reach not only to express it linguistically but bodily, orally and emotionally. [18]. It is unlikely that medical imaging devices will ever be able to interpret or communicate this complex integration of corporeal and emotional experience we call pain. We are therefore reliant on a mutually trusting rapport between clinician and patient to create an environment in which effective two-way communication can take place.

Medical Anthropologist Arthur Kleinman argues for the value of integrating '*physiological, psychological and social meanings*' of pain and illness [19 - 21]. 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*' [22]. Academic and physician, Rita Charon, who coined the term narrative medicine, claims that '*one of the central aspects of pain medicine that is undetectably central to all of medicine is narrative*' [23] observing that '*built into the very nature of narrative is that it is shared*' 241]. It is in this context that images are proposed as a potential means of eliciting and sharing the narrative necessary for healing – in its broadest sense.

USE OF PHOTOGRAPHIC IMAGES AS A TOOL FOR ELICITING PAIN NARRATIVES

There has been a growing interest in the use of images, and in particular photographic images, to elicit narrative from those affected by trauma, illness or pain. Harrison's review of the use of visual methodologies in the social sciences starts from a premise that the visual has been, '*until recently, a neglected dimension in our understanding of social life, despite the role of vision in other disciplines*' [25]. This is changing and from as far back as artist and activist Jo Spence,[26 - 28] to more recent projects such as those of Alan Radley,[30 -32] Sara Bro [33] and Johanna Willenfelt [34] to current collectives such as Collen's Pain Exhibit [35 - 36], the work of Pat Walton exploring the everyday life of families living with chronic pain and its impact on interfamilial relationships, Susanne Main's work exploring the value of online exhibitions [37] and the flickr and tumblr sites examined recently by Tarr and Gonzales, [38] photographs are being used as vehicles through which those who are ill or in pain can communicate their experience to others, and through which they can seek to understand it themselves. In the face of often invisible and intangible experience pain sufferers have also turned to metaphor [6, 14], as well as images [39] and frequently to both. There is an innate urge to translate the private invisible experience of pain into something tangible and visible to others and both metaphor and visual images are a means of doing this.

Other projects have also capitalised on the need for a visual representation of pain asking patients to draw their experience [40 - 42]. The Pain T project set up by pain specialist Dr Dietmar Harmann, ran a series of art workshops in conjunction with art therapists where those with pain were invited to draw or paint their experience [43]. There has been a burgeoning of projects exploring digital means of representing pain visually such as McMahon's web-based Iconic Pain Assessment Tool - IPAT [44 - 45] and Stones' research into the value of picture-led tools for pain management

[46]. Closs et al [47] have recently attempted to test twelve images ‘*depicting sensory qualities*’ of pain for their use in differentiating between neuropathic and nociceptive pain. There is however an inbuilt problematic in assessing images for their ‘accuracy’ as it could be argued one of the characteristics of images is their openness to different interpretations and that there is no such thing as an ‘accurate’ or universal image.

Main argues creative methods can be used to communicate the experience of living with chronic pain when expression through language fails [37]. Many film makers and performance artists have offered insights into the experience of living with chronic illness and pain, for example Stephen Dwoskin (*Pain is ... and intoxicated by my own illness*), Bob Flanagan, Martin O’ Brien, and Laura Dannequin’s performance work based on her personal experience of living with chronic pain [48]. There is thus a trend towards making visual sharable representations of pain and illness, which are outside the body [61].

REASONS FOR INVESTIGATING IMAGES AS AN ALTERNATIVE LANGUAGE WITH WHICH TO COMMUNICATE OR SHARE PAIN EXPERIENCE

Limitations of current medical measures and need for an alternative measure for evaluating pain

Most current medical pain measures commonly provide pre-existing verbal or numerical scales/lists to select from such as the verbal rating scale (VRS), visual analogue scales (VAS), Brief Pain Inventory and the McGill Pain Questionnaire (MPQ). These can fail to capture experience as complex and multifaceted as pain as

well as failing to provide opportunities for patients to generate their own language. The McGill Pain Questionnaire (MPQ) asks patients to constrict their experience into pre-existing formulae, a list of 78 different adjectives. It thus denies people with pain an opportunity to create their own metaphors using language drawn from their own social worlds. It is in the struggle to find apposite words, to create new descriptors, that more unusual and individually significant words emerge. The subtitle of Scarry's seminal tome [4] references the making and the unmaking of the world following pain. A re-making of the world following pain happens largely through language, it is vital this language is drawn from sufferers' own worlds and photographs are one means of generating such language.

Impact of inadequate means of expressing or measuring pain

Pain experiences are not easy to fit within the existing reductive measures or frameworks into which the medical system tries to place them such as rate your pain on a scale of 1 to 10. This serves to increase the isolation of sufferers in turn affecting pain experience itself [49]. There is now considerable evidence that pain and emotional processing systems interact [50 - 54]. It follows that discussion of the emotional impact and/or components of pain could not only reduce isolation but be pivotal to healing. If photographic images can catalyse patients' own language, it should be easier for those witnessing pain to enter the worlds in which that pain is happening, share the burden of pain and discuss mutually agreeable treatment plans more fruitfully.

Overview of the *face2face* photographic project, 2008-2013

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; a study piloting the image resource as a pack of 54 PAIN CARDS in pain consultations [10] and an artist's film focusing on doctor-patient dialogue and the role of narrative, positively reviewed in the medical and general press [55].

In contrast to *Perceptions of Pain* *face2face* focused mainly on facial pain. Facial pain has all the difficulties associated with musculo-skeletal pain as well as additional ones specific to the face. The canvas most of us use to express pain is the face, and yet when that canvas is itself in pain, it is difficult to express in a way which others can read accurately

Face2face: Research questions

Initially the overall research question we asked was:

Could a visual language provide an alternative means for communicating pain?

During the research and analyses we developed a more nuanced approach asking:

Can, and if so, how can photographs of pain placed between clinician and patient improve dialogue and rapport in medical pain consultations? Can photographs

generate an expanded and richer vocabulary capable of bridging the space between the person in pain and the person witnessing/treating it? Can photographic images re-balance the patient-clinician encounter and improve the quality of communication and interaction in the consulting room?

AIMS & METHODOLOGY

A key aim of co-creating images of pain with sufferers was to make pain visible and sharable with the hope of improving mutual understanding between those witnessing and those experiencing pain. Individual workshops aimed to co-create 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 their treatment journey; before, during or after management/treatment in order to prevent those with pain from being trapped not just within their pain but within a single negative image. By working with people with pain at different points in their management journey we were able to produce a collection of images reflecting a broad range of intensities and pain qualities. This arc of time allowed the images to represent changes sufferers had made in their perception of pain and to reflect a sense of movement and transformation, where present. Working at different points in the management journey was a way of addressing the sense of stasis and paralysis so often accompanying the language and experience of chronic pain states as well as a means of eliciting pertinent narrative and significant emotion to surface to be discussed.

The basic method of co-creating images with pain sufferers has been reported fully in several publications [10, 11] but a brief summary follows.

Face2face: sessions co-creating the photographs

The bulk of the creative practice of the *face2face* project involved co-creating portraits or images of their pain with five pain patients from UCLH with different types of facial pain. During *perceptions of pain* I had developed a process of co-creating images with pain patients, which aimed to give visual form to each person's unique experience of pain. Combining the creativity and strengths of pain sufferer and artist enables us to arrive together at a stronger series of images than either I or they would have arrived at alone, able to resonate with people outside the process. Patients who co-create images directly control how their pain is visualised and represented to others, rather than being placed on the receiving end of the medical gaze.

The sessions were individual mostly in rooms booked in the hospital but occasionally at other significant locations chosen by participants, for example walking round London looking for derelict buildings or in a participants' garden in West Hampstead. All sessions were audio-recorded and later transcribed. They numbered between nine and twelve and happened at three points during the treatment journey over a period of six to twelve months - before, during and after management/treatment. 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, and produced 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. The lengthy time-frame addressed the sense of stasis and paralysis so often accompanying the language and experience of chronic pain.

Sessions usually began by the person with pain talking about their experience. Questions would be posed such as how their pain might be visualised, were there any metaphors they already had for it, could pain be reflected through any particular materials, colours, light - or the absence of, or via significant objects they had brought with them? (All participants had been asked to bring in an object which they felt represented something of their experience of pain). Objects were used to stand in as metaphors for pain, shifting the discussion towards something with personal rather than collective meaning and providing a starting point for the photographic process. Photographs were taken by the artist, using a high-resolution digital camera, in discussion with the person with pain who often set up the objects within the frame. In subsequent sessions the images would be uploaded onto a computer and reviewed together and discussed. A selection of those deemed successful as photographs and close to the sufferer's experience was later made by artist and patient together. They would either then be modified following the session either by the artist, or by the person with pain through printing/stitching onto or collaging, or the photograph would be re-taken during the next session and refined as the focus of the image and what an individual wanted it to communicate became more clear. The process brought out the unavoidable relationship between personal narrative and pain experience.

Although predominantly it was objects which were used as metaphors for pain, the photographs produced can also be seen as 'portraits of pain'. Very few participants depicted the actual body, although in some cases the face or body was

represented in a figurative way, but usually within metaphoric environments. The images re-enforce Elkin's view that 'every picture is a picture of the body', (56) though in this context it might be closer to say 'every picture is a picture of the self'. The process was negotiated differently with each person who participated and would have been more successful at times than others in re-presenting the illness experience of another 'accurately'. In some ways the portraits produced are a fusion of objectivities as much as of subjectivities, - the distance the photograph provided was used to 'observe', 'witness' and 'unpick' some of that pain experience, rather than present it as fixed and stable. Carlin and Cole, in their analysis of *perceptions of pain*, support this argument: 'Padfield makes the case for objectifying pain by means of artistic representation so that sufferers can disassociate the pain from their being.' (57). Photographic portraits and the identities constructed within them are able to remain 'unstable' eliciting different narratives and allowing for the possibility of uncertainty and the not yet known, an essential part of being human and perhaps of accepting the chronic pain experience.

A selection of the images produced were integrated with images from the earlier *perceptions of pain* project and used to form a pack of pain cards designed as a communication tool for pain clinics. The impact of piloting these cards in the pain clinics of ten experts from a range of specialities is still being analysed but initial results suggested that changes occur. The images appear to elicit description of the emotional impact and components of pain as well as impacting on the non-verbal communication. For example what is also becoming apparent from observing the consultations is that the space between clinician and patient becomes far more active with greater non-verbal interaction and a more conversational rather than

interrogative style of verbal communication. One question is whether this can influence a more negotiated relationship during the rest of the consultation. This is something we are currently exploring in more depth.

(For further discussion of their impact on pain consultations please see 58 - 60).

Results of the co-creative process

What became interesting was the way that the co-creative process itself generated a different type of language and vocabulary around pain. For example one patient described how she saw her pain *'as red and black ... all distorted and kind of chaotic, and hopeless, an all-consuming kind of thing. It would definitely be something that's fragmented, damaged, torn, destroyed looking ... I feel my whole personality, who I am and what I want to do, is destroyed... demolition in progress'* (FIGURE 3.1 HERE). Another recounted *'the wires touch each other like this when the pain is most severe'* (FIGURE 3.2 HERE), another the isolation of when her family were able to go to the gym but she couldn't *'I can't do anything at the gym, I can't eat healthy fruit. It's like being behind glass or perspex; a barrier really. When it's not under control I can't do the simplest things. It's this contact with other people. That's the barrier'*. The image-making process as well as the images themselves appeared to shift conversation away from crystallised 'stories' or histories and more towards specific details that individuals wanted or needed to communicate about their pain.

DISCUSSION OF THE PHOTOGRAPH

Agency, ambiguity and specificities of the photographic medium

In a paper discussing ways in which photographs can elicit narrative following a study giving cameras to hospital in-patients, Social Psychologist Prof Alan Radley noted that '*The photographs gained their meaning from the act that produced them; they were not meaningful only in the sense of their pictured content*' [61].

Photography can be seen as not just a medium but a process, '*a way of making known and shaping experience*' [62]. The fact that pain sufferers were involved in producing the photographs in *face2face* is perhaps important not only to them but to future patients reviewing them in the clinic.

Photographs do not just allow us to recollect personal experience; they also create it. According to photographic theorist John Tagg, the production of images 'animates' rather than 'discovers' meaning [63 - 64]. It is therefore vital that pain sufferers play an active role in both the creation and the interpretation of images representing their experience. Meaning is being both constructed and revealed during the co-creation process and during review in the clinic. Having control over how their pain and illness is visually represented is essential for any sense of autonomy and wholeness and any sense of responsibility in the recovery process. Control of the lens confers power over how an illness is seen and understood by others, as Jo Spence demonstrated so powerfully with her own illness [26]. 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, and it is suggested that the process can only be beneficial when sufferers have considerable agency within it. Of her images post-surgery one *face2face* participant wrote '*I've started drawing where I*

would like to be after the surgery. I found just what I was looking for, a transparent ball, that I want to put all the photographs and drawings and pins connected with my facial pain inside and have a photograph taken of me kicking it into the distance or throwing it into the air. They are still there, but they are contained within the ball and I can throw it far away. I will have control over it. They will be trapped within the glass and I will be outside of it, instead of behind it' (FIGURE 3.3 HERE).

Another reason that photographic images might help negotiate a more 'democratised' interaction in the clinic between patient and clinician might be due to their ambiguity. It is easier to recognise that we all ascribe different interpretations to photographs than to words, even though in the case of the latter it may still be true [65]. Photographs force us to recognise the chasm between our different perspectives and the limits of language available to us to cross this space. As a result we are forced to mediate the image via language and vice versa to unravel enough meaning to arrive at a shared understanding. Photographs of pain used within medical consultations can help equalise the physical, linguistic and metaphorical space of the consulting room, provoking the co-creation of new ways of 'knowing' illness and pain. Patients used the images to describe pain experience in their own words and its significance for them, for example the image of a broken chain (FIGURE 3.4 HERE), which had been co-created with someone with back pain, in the clinic elicited discussion of the gap experienced in family relations '*and this one it's like a gap, ... sometimes I feel a gap between my family ... they say they haven't got no time ... Christmas as well not all of them is going to come*' (PK3). The same image elicited a different interpretation in another consultation '*it seems that I've got a lot of links that don't connect*' (PC3). One patient used graphic language to describe the quality and impact of pain in response to the photographs '*as if something is being gouged in the*

ear and twisting round and round, so I picked them for that reason. This one is when it's at its most severest, like knife pains ... That's when it gets to the point, I can't take no more' (PA4), and another frequent refrain *'my GP doesn't listen to me anymore'* (PB3).

The materiality of the photograph as well as its ability to document in some way facilitates empathy and validates the experience of another. Handling the photographs backwards and forwards confers an agency on the images in a Gellian sense, effecting and building social relations [66]. In the following passage the image becomes a shared reference point:

<CH4>*What about this, card number five?*

<PH4>*That would bring tears and weeping from the eye and that.*

<CH4>*Yes, so the electric shock like*

<PH4>*Yes.*

<CH4> *The sparks flying off is, ah, giving me... or telling me a bit about what the pain feels like. Is that what you're getting at?*

<PH4>*That's it, yes.*

<CH4>*Okay. What this about?*

<PH4>*That's with the eye, you know, when it'll hit the eye. I just have to hold my eye. And then this will start weeping and that. The eye will turn red.*

<CH4>*Yes.*

<other UH4>*Didn't you think when you were embarrassed as well, that, kind of...*

<PH4>*Yes, it could be we're sitting having a conversation with you and all of a sudden it would start, just no warning.*

<CH4>*Yes. It's quite interesting you mentioned about embarrassment. Tell me a bit more about that.*

In analysing the photographs produced during *Perceptions of Pain*, Cole and Carlin argued images were able to ‘*span the seemingly unbridgeable gap between the one who suffers pain and the one who hears about pain*’ [57] labelling them as ‘*metaphorical self-portraits*’. The corporeality of the images, the way that the images as photographic objects hold feelings and memories of the body creates, holds and elicits memory from both patient and clinician. Additionally the polysemy of photographs allows for a multiplicity of readings revealing what the sufferer/viewer needs to focus on at that moment. We can employ the polysemy of photographs to help us understand experience alien to us, to tolerate complexity and ambiguity, and the pain of not knowing, of not having an answer. Pither [67] argues that clinicians need to help patients as well as themselves to tolerate ambiguity, unknowing and uncertainty. The image-making and image-reviewing processes can allow difficult aspects of experience to enter the discussion which might not easily make their way into a medical space encouraging a toleration of uncertainty.

Face2face: Portraits of pain: pain and identity

Although predominantly photographs of objects the *face2face* images could also be seen as ‘portraits of pain’. In a sense they are the opposite of Mark Gilbert’s portraits which show the visible differences in the faces of patients following maxillofacial surgery [68]. Conversely the *face2face* photographs focus on and make visible the invisible changes in identity following pain. Very few patients chose to depict the body, though some did (FIGURE 3.5 HERE). The photographs re-enforce Elkin’s view that ‘*every picture is a picture of the body*’,[56] although it might be

more accurate to say '*every picture is a picture of the self*'. In some ways the portraits produced are a fusion of objectivities as much as of subjectivities - the distance the photograph provided [69] was used to 'observe', 'witness' and 'unpick' pain experience, rather than present it as fixed and stable. Carlin and Cole support this argument: '*Padfield makes the case for objectifying pain by means of artistic representation so that sufferers can disassociate the pain from their being*' [70]. Photographic portraits and the identities constructed within them are able to remain 'unstable' eliciting different narratives allowing for the possibility of uncertainty and the not yet known - an essential part of being human and perhaps of the chronic pain experience.

This elasticity of identity is further extended through the process of creating multiple portraits over time. Working with people at different points in their pain journey allowed multiple and changing perceptions of pain and identity to emerge. Aspects of experience, which perhaps neither patient nor artist knew were there, could be revealed over time. Could such a reciprocal relationship have implications for the clinician's role in the uncovering of significant narrative *with* and not *for* patients in the context of chronic pain? Directed by the person in pain, the camera allowed significant moments of narrative to be revealed. Kozloff, speaking of Nan Goldin's work describes a fluidity of 'raw contact' [71] between photographer and subject. The co-creation process at best is an example of raw exchange, capturing through the medium of photography that which is not normally seen; that which is within the power of the subject to choose to reveal or conceal. Jane Fletcher describes the photographic encounter as:

two or more people in some sort of dialogue – be it a collaboration or a battle of wills. Two or more people co-operating with or resisting, one another [72].

It is in a spirit of dialogue that these images are best used in the clinic. In other words a key contribution of the photograph to the clinic is in the space it creates for negotiation - for unraveling meaning together.

Reflections on the image in medicine

In her paper in *Medical Humanities* on how the diagnostic image confronts the lived body in the consulting room Stahl describes how *'the medical image, presented to the patient by the physician, participates in medicine's cold culture of abstraction, objectification and mandated normativity'* [73].

From observation of the use of the *face2face* images within pain consultations [9, 10, 65] **I** would argue conversely that photographs of pain co-created with pain sufferers, integrate the patient's body into the image, allowing their lived experience to become visible and present in the consulting room, addressing the objectification of which Stahl speaks. The subjective experience of pain can then become sharable within a medical framework as it becomes real and visible to the clinician, currently trained to rely on 'evidence' rather than narrative. Stahl asserts that the medical image, *'far from a piece of objective data, testifies to the interplay of particular beliefs, practices and doctrines contemporary medicine holds dear'* concluding that *'to best treat her patient, the physician must appreciate the influence of these images and appropriately place them within the context of the patient's lived experience'* [74]. In *face2face* the images were co-created with patients, their selection in clinic made by sufferers and it is sufferers who influence their interpretation. Thus instead of testifying to the beliefs of clinicians, they testify to the beliefs of patients.

There is a potency at the intersect of pain, language and image where new language can be born from patients own social and linguistic worlds which would not only allow patients but clinicians to tolerate the uncertain irrational nature of pain experience and move forward together discussing its management in the context of that individual patient's life.

CONCLUSION:

Photographic images can give tangible form to confusing sensations providing a shared aesthetic space within which to negotiate, both with the 'other' and with attachment to previously held perceptions. It is the collaborative search for meaning they stimulate within the consulting room, which potentially validates the pain cards as a communication tool.

Bleakley argues '*Medicine must democratise ... improved communication lowers patient risk in reducing medical error. The arts ... provide the media through which such democratisation can be learned*'[75].

Face2face is the first project to study in-depth the impact of using photographs of pain as an intervention in clinician-patient dialogue across a multi-disciplinary team of experts in an NHS hospital using video recordings which can be compared with self-reporting evaluation forms. From the results beginning to emerge, the images appear to generate new language, enriching pain descriptions and facilitating discussion of emotional aspects of pain significant to its intensity and prolongation for that individual. They could also play a role in teaching healthcare professionals to raise awareness of chronic pain and its attendant suffering. The authors suggest these early findings warrant further interdisciplinary

analysis/investigation to assess and validate the images as a new communication tool for improving doctor-patient dialogue across the NHS and argue that photographic images and image-making processes should be considered valuable tools for democratizing medical pain encounters.

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REFERENCES:

- 1 Hjerstad M J, Fayers P M, Haugen D F, *et al.* Studies comparing Numerical Rating Scales, Verbal Rating Scales, and Visual Analogue Scales for assessment of pain intensity in adults: a systematic literature review. *J.Pain Symptom.Manage.* 2011;41:1073-1093.
- 2 Morse J M. Using qualitative methods to access the pain experience. *British journal of pain* 2015; 9:26-31.
- 3 Deignan A, Littlemore J, Semino E, editors. *Figurative language, genre and register.* Cambridge: Cambridge University Press, 2013:267-304
- 4 Scarry E. *The body in pain: the making and unmaking of the world.* Oxford: Oxford University Press,1985.

- 5 Charon R. 'A Narrative Medicine for Pain', in Carr D, Loeser J, Morris D, (editors) *Narrative Pain and Suffering: Progress in Pain Research and Management* Vol 34. Seattle: IASP Press, 2005.
- 6 Biro D. *The language of pain. Finding words, compassion and relief*. New York: WW Norton & Co, 2010.
- 7 Bourke J. Pain and the politics of sympathy, historical reflections, 1760s to 1960s (Utrecht: Universiteit Utrecht). *Back to Context* 2011,10.
- 8 Padfield D. Mask:Mirror:Membrane. *PAIN NEWS* 2012;10(2):104 – 109.
- 9 Padfield D. Unpublished PhD dissertation, University College London, 2013.
10. Padfield D, Zakrzewska J M, Williams A C deC. Do photographic images of pain improve communication during pain consultations? *Pain Research & Management* 2015;20(3):123 – 128.
- 11 Padfield D. *Perceptions of Pain*, 1st edition. Stockport: Dewi Lewis Publishing, 2003.
- 12 . Padfield, D, Janmohamed F, Zakrzewska JM *et al*. A slippery surface, can photographic images of pain improve communication in pain consultations? *International Journal of Surgery*, 2010;8(2)144–150

- 13 Bleakley A. Association of Medical Humanities Conference Programme, 2015:3
- 14 Biro D. 'Psychological Pain: Metaphor or Reality?' In: Boddice R. ed. *Pain and Emotion in Modern History*. Basingstoke: Palgrave Macmillan, 2014:53 – 65.
- 15 Biro (6):104
- 16 Bourke J. *The story of pain: from prayer to painkillers*. Oxford: Oxford University Press, 2014
- 17 Good BJ. 1994. *Medicine, Rationality, and experience: An anthropological perspective*. Cambridge: Cambridge University Press.
- 18 Boddice R. (editor) *Pain and Emotion in Modern History*. Basingstoke: Palgrave Macmillan, 2014.
- 19 Kleinman A. *The illness narratives, suffering, healing & the human condition*. USA: Basic Books, 1988.
- 20 Kleinman, A. Catastrophe and caregiving: the failure of medicine as an art. *Lancet* 2008;371:22–23.

- 21 Kleinman, A. Care: in search of a health agenda, *Lancet* 2015;386: 240-241
- 22 Green CR. Being present: the role of narrative medicine in reducing the unequal burden of pain. *Pain* 2011;152:965-966.
- 23 Charon (5):29.
- 24 Charon (5) :30.
- 25 Harrison B. Seeing health and illness worlds – using visual methodologies in a sociology of health and illness: a methodological review, *Sociology of Health & Illness* 24 2002;(6):856.
- 26 Spence J. *Putting Myself in the Picture*. London: Camden Press, 1986.
- 27 Martin R, Spence J. ‘New portraits for old: the use of camera in therapy’. In: Betterton R, ed. *Looking on: images of femininity in the visual arts and media*. London: Pandora, 1987:267–79.
- 28 Dennett T. ‘Jo Spence’s auto-therapeutic survival strategies’. In: Bell S. and Radley, A. eds. ‘Representations of illness and disease’. *Health* 2011;15(3):223 -239.
- 29 Radley A, and Taylor D. Images of recovery: A photoelicitation

- study on the hospital ward. *Qualitative Health Research* 2003;13:77–99.
- 30 Radley A, Hodgetts D, and Cullen A. Visualising homelessness: A study of photography and estrangement. *Journal of Community and Applied Social Psychology* 2005;15:273–95.
- 31 Radley A. *Works of illness: narrative, picturing and the social response to serious disease*. Ashby-de-la-Zouch, UK: InkerMen Press, 2009.
- 32 Radley, A. What people do with pictures. *Visual Studies* 2010;25(3):268 — 279.
- 33 Henriksen N, Tjornhoj-Thomsen T, Ploug Hansen H. ‘Illness, everyday life and narrative montage: The visual aesthetics of cancer in Sara Bro’s Diary’. In: Bell S. and Radley A. eds. ‘Representations of illness and disease’ *Health* 2011;15(3):277-297.
- 34 Willenfelt J. ‘Documenting Bodies: Pain Surfaces’. In: Boddice R. ed. *Pain and Emotion in Modern History*. Basingstoke and New York: Palgrave Macmillan 2014: 260 – 276 (or do I use Boddice (18) here?)
- 35 Collen M. Life of pain, life of pleasure: pain from the patients' perspective - the evolution of the PAIN exhibit. *J Pain Palliat Care Pharmacotherapy* 2005;19(4):45-52.
- 36 Collen M. PAIN <http://painexhibit.org/> accessed 5th August 2014.

- 37 Main S. Picturing Pain: Using creative methods to communicate the experience of chronic pain, *Pain News* 2012;(1):32-35.
http://www.britishpainsociety.org/bps_nl_vol12_issue1.pdf
- 38 Gonzalez-Polledo E, Tarr J. The thing about pain: The remaking of illness narratives in chronic pain expression on social media. *newmedia & society* 2014: 1-18
- 39 Davis FD. 'The problem of pain'. In: Giordano J. ed. *Maldynia, multidisciplinary perspectives on the illness of chronic pain*. New York: Taylor & Francis, 2011: 243-255.
- 40 Wilkinson M, Robinson D. Migraine art. *Cephalalgia* 1985;5(3):151-157.
- 41 Broadbent E, Niederhoffer K, Hague T, et al. Headache sufferers' drawings reflect distress, disability and illness perceptions. *J Psychosom Res* 2009;66:465-470.
- 42 Maclean S. Exploring the use of drawings for patients communicating chronic pain to healthcare professionals. *Pain News* 2009;Winter:34-37.
http://www.britishpainsociety.org/bps_nl_winter_2009.pdf
- 43 Geller, B. The PainT project. *Pain News* 2011;Winter:42-43.

- 44 McMahon E, Wilson-Pauwels L, Henry J, *et al.* The Iconic Pain Assessment Tool: Facilitating the Translation of Pain Sensations and Improving Patient-Physician Dialogue. *Journal of bio-communication* 2008;34(2): E20 – E24.
- 45 Lalloo C, & Henry JL. Evaluation of the Iconic Pain Assessment Tool by a heterogeneous group of people in pain. *Pain Res Manage* 2011;16(1):13-18.
- 46 Stones C. Positively picturing pain? Using patient-generated pictures to establish affective visual design qualities. *International Journal of Design* 2013;7(1):85-97.
- 47 Closs SJ, Knapp P, Morely S, *et al.* Can pictorial images communicate the quality of pain successfully? *British Journal of Pain* 2015; 1-8.
- 48 Dannequin L. *Hardy Animal*. AMH Conference 2015.
- 49 Eisenberger NI, Lieberman MD, and Williams KD. Does rejection hurt? An FMRI study of social exclusion. *Science* 2003;302/5643:290-92.
- 50 Tracey I. ‘Objectifying pain through brain imaging’. In Carr D, Loeser J. and Morris D. (editors) *Narrative Pain and Suffering: Progress in Pain Research and Management* 2005;vol 34: Seattle, USA: IASP Press:137

- 51 Carr D, Loeser J. and Morris D. eds. *'Narrative Pain and Suffering: Progress in Pain Research and Management Vol 34*, Seattle, USA: IASP Press. 2015.
- 52 Tracey I. and Mantyh, P. The Cerebral Signature for Pain Perception and Its Modulation. *Neuron* 2007;55(August 2):377 – 391.
- 53 Wiech K and Tracey I. The influence of negative emotions on pain: Behavioral effects and neural mechanisms. *NeuroImage* 2009;47:987–994.
- 54 McMahon SB. and Koltzenburg M. *Textbook of Pain*, 5th Edition. London: Elsevier, 2006.
- 55 Jones D. Portraits of Pain. *Lancet* 2011;378(9789)July 30:391..
- 56 Elkins J. *Pictures of the body: Pain and metamorphosis*. Stanford: Stanford University Press,1999:1
- 57 Carlin N, Cole T. Maldynia as muse: A recent experiment in the visual arts and medical humanities. In: Giordano J, ed. *Maldynia, multidisciplinary perspectives on the illness of chronic pain*. New York: Taylor & Francis, 2011:105.
- 58 Padfield D. Zakrzewska JM. Encountering Pain. *Lancet* 2017: 389 (in press)

- 59 Semino E. Zakrzewska JM. Williams A. Images and the dynamic of pain consultations. *Lancet* 2017; 389: 1186-1187
- 60 Padfield D. Chadwick T. Omand H. The body as Image: Image as body. 2017: 389 (in press)
- 61 Radley (44):270
- 62 Radley (44):270
- 63 Tagg J. Power and Photography: Part One, A Means of Surveillance: The Photograph as Evidence in Law. *Screen Education* 1980;36(autumn):17–55.
- 64 Tagg J. *The Disciplinary Frame: Photographic Truths and the Capture of Meaning*. Minneapolis: University of Minnesota Press, 2009:1.
- 65 Padfield D. Representing the ‘pain of others’ in Bell S. and Radley A. eds. Another way of knowing; Art, disease and illness. *Health* 2011;15(3):241-258.
- 66 Gell A. *Art and Agency, An Anthropological Theory*. New York, Oxford: Clarendon Press,1998.
- 67 Pither C. Pain clinic is not a place for diagnosis. *Pain news* 2011(Winter):21.
- 68 Gilbert M. *Saving Faces*. Exhibition of portraits by Mark Gilbert. National Portrait Gallery, London. 2002.

- 69 Sontag S. *On Photography*. London: Penguin, 1978
- 70 Carlin & Cole (20):105.
- 71 Kosloff M. 'Real faces' in *Lone Visions, Crowded Frames: essays on photography*. Albuquerque: University of New Mexico Press, 1994:76-78.
- 72 Fletcher J. 'Sweet Liberties: Narratives of Resistance and Desire'. In Newton K. and Rolph C, (editors), *Masquerade: Women's Contemporary Portrait Photography*. Cardiff: Ffotogallery Publishing, 2003:51.
- 73 Stahl D. Living into the imagined body: how the diagnostic image confronts the lived body. *MedHumanit* 2013;39:53–58.
- 74 Stahl (84):53-54.
- 75 Bleakley (13):11

LEGENDS FOR FIGURES

Figure 3.1

Image of pain co-created by Deborah Padfield with Liz Aldous from the series *Face2Face*, 2008-2013 © Deborah Padfield.

Figure 3.2

Image of pain co-created by Deborah Padfield with Chandrakant Khoda from the series *Face2Face*, 2008-2013 © Deborah Padfield.

Figure 3.3

Image of pain co-created by Deborah Padfield with Alison Glenn from the series *Face2Face*, 2008-2013 © Deborah Padfield.

Figure 3.4

Image of pain co-created by Deborah Padfield with John Pates from the series *perceptions of pain*, 2001-2006 © Deborah Padfield.

Figure 3.5

Image of pain co-created by Deborah Padfield with Yante from the series *Face2Face*, 2008-2013 © Deborah Padfield.