

Absence and presence: the potential for art to facilitate improved communication around pain – reflections from the British Society of Haematology (BSH) Conference 2019

My most vivid memory of the BSH conference is of going to meet Dr Stephen Hibbs (our chair) and getting a message that neither he nor one of the other speakers, Mary Ayinde, could meet as Mary had had a sickle cell crisis getting off the aeroplane at Glasgow airport and had had to go straight to hospital instead of the conference centre. It brought vividly into focus the way that pain is not an abstract concept for intellectual acrobatics, it has tangible and severe impacts on people's lives. The absence of Mary spoke more than any of our presences. In the end, Stephen read out words written by Mary on her behalf and each word was re-enforced by the physicality of her absence and the presence of the pain which underscored them and prevented her from being there.

Not only is the physical impact of this pain difficult to bear, but like an octopus the tentacles of sickle cell stretch out into every aspect of life. So, sometimes I make plans and they fall through because of a sickle related issue. When I word it like that, it sounds so simple. But imagine agreeing to speak on something you are passionate about almost a year in advance. Booking time off work, preparing for your speech, booking your flight, hotel, etc, only to get to the destination and fall into crisis and 12 hours before you are scheduled to speak. Well that's exactly what has just happened to me. Imagine this being something I experience frequently. Then comes the emotional pain of constantly feeling inadequate and constantly letting others down, both in my professional life and private life. Trying to structure a "normal" life around these bouts of pain is quite difficult. And doctors can help reduce the severity of a crisis, and consequently the longevity of it, by listening to the patient (Mary Ayinde).

I don't experience the crises of sickle cell attacks Mary lives with, nor the pain of bleeds that haemophilia patient Jorrell Sebastian suffers from (whose humour nevertheless infused the session) but I do live with pain from an auto-immune condition, antiphospholipid syndrome, and struggle with its invisibility, unpredictability and impact on my daily life as a visual artist and an academic. There is an urgency in pain that demands to be heard and which creates a chasm between the person living with it and the person witnessing it. Although currently I have a wonderful haematologist at Guy's and St Thomas' and receive what I consider some of the best treatment possible, in the past I experienced some of the worst and realise that communication, as Prof Alan Bleakley (2013) reminds us, is often at the heart of what goes well and what goes wrong in medicine.

Communication is at the heart of my work visualising pain. It was my pain specialist at St Thomas' Hospital, Dr Charles Pither who started me on this journey when we met at an INPUT event and discussed the frustrations we both had with the difficulty pain presented for communication alongside my photographic work exploring the pain of isolation or the isolation of pain. The discussions turned into a successful Sciart application and the *perceptions of pain* project which lead to a touring exhibition, pilot studies and a book of the same name. The question we were asking was could images provide an alternative language for pain able to accommodate its complex, multifactorial and deeply subjective nature? Could placing an image between a person with pain and a clinician, encourage increased empathy and mutual understanding?

In discussing the slant of the talk for the conference with Dr Hibbs, he spoke about the value of re-problematising pain and the negative impact of busy clinicians boxing pain into a simple algorithm in their mind or short form consultation with too much emphasis placed on numerical pain scores. I could not agree more and our attempts to move pain assessment from rate your pain on a scale of 1 to 10 to tell me about this image or why did you choose this image – aim to do just that. The desire is not to overwhelm already pressured clinicians, but to provide a tool that could rehumanise interactions around pain, allowing space for ambiguity and toleration of uncertainty, not feelings that sit easily in the clinic.

Face2face is a recent collaboration with facial pain consultant Prof Joanna Zakrzewska and staff and patients from UCLH which picked up many of these themes. The question became not could images replace language but in what ways could images regenerate

language around pain. Working closely with five people with pain on the pain management waiting lists at UCLH I co-created photographic images of pain which reflected their unique experiences of pain during individual art workshops. That the images were co-created was very important so as not to re-appropriate the experiences of others as so often happens along the diagnostic corridors. These images were then integrated with earlier images from the perceptions of pain project and used to form a pack of 54 approx. 6" x 4" laminated images of pain or PAIN CARDS, rather like a large pack of playing cards. These cards were offered to other patients in the waiting room who had not been involved in making them. They were invited to select any that resonated for them and take them into their pain consultation to see if they facilitated communication or impacted on the interaction in any way. Ten clinicians from UCLH volunteered to have 17 consultations (in total) filmed (with consent). A multi-disciplinary team came together to analyse the footage, transcripts and post-consultation questionnaires and the results are very encouraging (see further reading) suggesting that images can be a meaningful way to open up dialogue in pain consultations, increase clinician-patient affiliation and elicit emotional disclosure, where relevant. They also appear to engage both clinician and patient in a triadic as opposed to dyadic construction of meaning around pain and its impact, bringing its significance for that individual into the centre of the frame.

I am not advocating that images replace pain measurement tools already used but I am suggesting they are a means of expanding the dialogue and improving clinician-patient interaction. We imbue the photograph, even in a digital age, with an ability to document 'truth' and for this reason it is an apposite medium with which to document and make present the subjective experience of others. A photograph provides a shared space as a reference point and its polysemy reminds us of the necessity of negotiating language in order to understand exactly what another might mean - your pain is not the same as my pain.

Suggested further reading:

Bleakley A & Marshall R (2013) Can the science of communication inform the art of the medical humanities? *Medical Education*; 47: 126–133

Omand H & Padfield D (2019) 'New Contexts: what art psychotherapy theory can bring to an understanding of using images to communicate the experience of pain in medical pain consultations' *ATOL: Art Therapy Online* 10 (2)

Padfield D (2019) 'Mirrors and shadows: Photography as a way of sharing pain experience in medical pain consultations' in Bruzzi S, Jung N (eds) *Beyond the Rhetoric of Pain*. Abingdon and New York: Routledge.

Padfield D, Omand H, Semino E, Williams A C de C, Zakrzewska JM (2018) Images as catalysts for meaning-making in medical pain encounters: a multidisciplinary analysis *Med Humanit*;44:74–81

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.

Semino E, Zakrzewska JM, Williams A, C de C (2017) Images and the dynamics of pain consultations. *Lancet* vol 389: 1186 - 1187

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

Look out for our forthcoming collection: Padfield D & Zakrzewska JM (eds) (2020 in press) *Encountering Pain*: London: UCL Press.