Finding a visual language for pain

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Believing is seeing

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Whatever pain achieves, it achieves in part through its unsharability, and it ensures this unsharability through its resistance to language ... to have great pain is to have certainty; to hear that another person has pain is to have doubt.

(Elaine Scarry, The body in pain)

It is precisely because pain, as Elaine Scarry suggests, defies expression in verbal language that it is so difficult to 'share'. This is one of the reasons why so many people who suffer from unrelenting pain experience equally intense feelings of isolation, despair and confusion. 'Pain' is invisible, leaving some patients, as Dr Pither acknowledges, feeling disbelieved and compelled to go to the ends of the earth to prove its reality so that someone will believe and treat them. This increases the intensity of their private internal relationship with pain and decreases the certainty of their relationships with the outside and the medical worlds. If my pain is not real then what else in my world is also unreal? As one patient said:

You can't see pain so people don't believe it. I had that even more so with doctors ... I could be crawling around the floor but it would not help ... One doctor sat there and said, 'You cannot be in the pain you say you are in.' I said, 'What do you want me to do to show you I am in pain?'

Many of the patients I worked with described similar feelings of frustration and embattlement.

Talking to Dr Pither, I discovered that doctors were as frustrated as patients by pain's resistance to language, and that he was interested in exploring within the pain management setting the possibilities offered by visual images. My own experience of illness and the encouragement I had received from my family doctor to draw and write about my pain, had made me aware of the value visual images could play in the health setting, as well as the importance of communication between doctor and patient and the need for patients' responsibility for their own recovery. It led me to ask the following questions: Could the immediacy of visual images provide an easier access route to a physician's understanding of a patient's experience? Could the co-creation of photographs, provide patients with a tangible visible representation of their
pain, thereby reducing the need to hang on to it in order to prove its existence? Could the distance a photograph provides allow all of us to look at aspects of our pain which were previously too close or 'painful' to acknowledge?

After many discussions with Dr Pither and some of his colleagues at the INPUT Pain Unit, St Thomas' (where I had been treated myself), we developed a collaborative project in search of a visual language for pain. We wanted to explore the interface between doctor and patient, photographer and subject, maker and viewer, science and art.

Having spent so long feeling powerless myself on the receiving end of the medical gaze, I was keen that patients had the opportunity to experience, as I had, some sense of control through photography and control of the lens. I felt it was as important for me as an artist to relinquish some authorial control as it was for the doctor to relinquish the need to provide an 'answer'. The space this left us in was not easy and was one of continual negotiation which varied from patient to patient. It was a highly collaborative process which pushed the images towards an aesthetic that they would never have arrived at had I been working alone. We owe a great deal to the courage, commitment and creativity of all the patients who volunteered.

What I found interesting during the process was the way that concentrating on the making of a photograph and the visual relationships of objects, rather than on verbal descriptors of pain, affected the verbal as much as the visual dialogues. We had many discussions around pain which I think could only have happened because of our shared aim of co-creating an image and the starting point that provided.

One sufferer talked about pain's dual role as a barrier/trap, and as a protection via a photograph of a curtain partially obscuring the building behind it, and a series of photographs of garden fences around flowers. She was also more able to describe her own experiences of living with pain through the drooping posture of a sunflower than by direct reference to herself.

'It is just in agony by the look of it; I caught it on a bad day. I didn't have a very good day that day. The head is down, it just seems as though it has ended its life, but what it will do this year, is it will shoot back up again. The roots are strong. It varies with me … this will come up again, yes.'

‘At its worst it feels like hot barbed wire.’ (Deborah Padfield with Linda Sinfield)

‘Time keeping was very much part of my life. It comes into your system and never leaves. The power source of the clock is a coiled spring. The power source in us is the heart. I have been revived from death. I am giving back something for what I have been given – life basically.’ (Deborah Padfield with John Pates)
Other sufferers referred to physical sensations such as coldness in the spine via metal rods, of weight and pressure through a stone next to a keyhole to 'let the pressure escape', of pain as an alien body via chewing gum tangled in wire, of heat in the spine through barbed wire on fire, restriction through a tyre being squeezed by a jubilee clip or a wrist being restrained and seared by wire, of low self-esteem through images of rubbish and negative words, the co-existence of polarised feelings through the use of mirrors and reflections, of isolation through a cement jacket floating in dark space and pain’s overwhelming of the consciousness as much as the body via a submerged head disconnected from the body as represented by an overflowing bath.

The images produced contain unique and highly personalised narratives but they also share many common themes – which are all too familiar to those of us suffering from chronic pain.

The collaborative process was extended when some of the patients took a selection of photographs to a follow-up consultation with Dr Pither to see if they could indeed act as springboards for a more mutually beneficial dialogue, and has been continued by feedback from visitors to the exhibitions.

This project has made me wonder whether access to image-making around other non-visible fears, such as fear of failure, of pain, of the unknown, might also benefit medical students. Could experience of the processes of the visual arts provide them with another ‘language’ or tool to understand and communicate with their future patients? There are several possibilities for future developments, such as the involvement of a psychologist/therapist, or the extension of the bank of images to something which might be of general value. A book is planned for next year. We have arrived at a beginning and not an endpoint.

There are many individuals and institutions who have supported us and this project to whom we owe a great debt of gratitude. Acceptance of each other’s experience is a useful starting point for any dialogue. Several articles on this project have referred to the aphorism that ‘seeing is believing’. Maybe conversely believing is the first step to seeing.

Acknowledgement

The initial research was funded by a Sciart Research Award for 2001. The exhibition was first shown at the Sheridan Russell Gallery, London, and subsequently at St Thomas’ & Guy’s Hospitals, made possible by a generous grant from the Guy’s and St Thomas’ Charitable Foundation. It was designed and curated by Elaine McLaren, and was shown recently at the RCP, where it was sponsored by an unrestricted educational grant from Novartis.

Reference