

# Finding a visual language for pain

Charles Pither

**Charles Pither**  
FRCA, Consultant  
Pain Specialist,  
St Thomas'  
Hospital, London

*Clin Med JRCPL*  
2002;2:570-1

*Are words actually any use to describe what pain really feels like? Words only come when everything is over, when things have calmed down. They refer to memory and are either powerless or untruthful.*

(Alphonse Daudet)

Pain is the protean symptom: trawl through the small print on any illness and somewhere you will read it can cause pain.

For the postoperative patient, when the source is a large hole in the integument, an analysis of the sensory experience is hardly necessary. It hurts, and appropriate doses of a suitable analgesic will normally solve the problem. Personal experience of the knocks and injuries of daily life inform our ability to empathise sufficiently to fulfil our caring role. Whether the pain is slightly more burning, or a little less sharp is largely irrelevant. Pain in this context has no diagnostic value – it just needs to be treated.

What if the patient reports in vivid terms that the pain in the left upper chest is so agonising that it resembles flaming barbed wire being dragged across the skin? More comprehensible, perhaps, if they were writhing on the floor, clutching the affected area in best Hollywood style. But they are not. They walked into the office and are now sitting opposite you, well dressed and calmly spoken, with not a single abnormal finding after two years of investigation.

How are we to make sense of this? What is it this person is experiencing that has had such a terrible impact on the quality of their life and yet we simply cannot explain in medical terms? We have no facility to understand the language of such an encounter.

Sitting listening to pain sufferers describe the difficulties of trying to make doctors understand their experience reveals the unhappy consequences of this unequal struggle. Doctors seldom fail to transfer some of our bafflement back to our patients. They end up feeling disbelieved and all too often dismissed. They soon start to doubt the doctor and end up doubting themselves. The consequences range from anger and resentment to depression and withdrawal. In the words of Wittgenstein 'whereof one cannot speak thereof one must remain silent'.

A more detailed analysis of the phenomena of pain descriptors adds another slant: how many times have we heard it said that a pain is stabbing? – 'Just like being stabbed with a knife, doctor.'

I have sought out as many stab victims as I can and asked them what it felt like when it happened. The

boxing trainer stabbed in the back in a fight during an England football game in a pub in the East End just felt cold. Monica Seles reported being punched, others describe a pricking sensation. Often there is no pain initially. No one has told me it was like being stabbed.

In truth the ability of our wondrous sensory detection systems to distinguish between a stab wound and blunt injury is very limited. The true pain comes with the sight of blood and realisation of what has happened. This seems at odds with the myriad of patients who daily report to their doctors that they experience a stabbing pain. Being stabbed actually does not hurt that much. What really hurts is the damaging conviction that something awful has happened, and the 'virtual reality' of a knife being plunged into the chest. The most important part of the evaluation of a pain sensation is related to the imagery that it conjures up in the mind's eye. This in turn is fuelled by interpretation which is based on past experience, knowledge, and intuition. It rapidly provokes emotions related to threat, helplessness and fear. These become intrinsic to the pain experience. The anxious, fearful person brought up with surety of the evil and threatening nature of pain, who tends to catastrophise and feels powerless in the face of illness will tend to suffer more when a pain does not resolve. (As, for example, commonly occurs with simple back pain.) Verbal language can never adequately express the complexity of this pain experience.

The logical question for the interested party is 'then are there alternative ways?'

Might it be meaningful to allow a pain sufferer to express what they see in their mind's eye?

What do pain sufferers come up with when given the opportunity to explore a visual language for pain?

The photographic artist Deborah Padfield, herself familiar with chronic pain, and myself a pain specialist received a SciArt grant to investigate this question. The research question was to investigate to what extent pain sufferers could use a visual medium to express what it was they experienced. We called it '**finding a visual language for pain**'.

Deborah worked with ten chronic pain sufferers attending our interdisciplinary cognitive behavioural pain management programme at St Thomas'. Over a series of, often protracted, interviews they initially described their pain and how they 'saw' it. They then

worked on ideas for images which Deborah photographed, either solely or with their assistance. The resultant images were reviewed in further sessions. The images that best expressed their experience were chosen by the subjects and the process reiterated until they were happy that the image 'said something' to them in terms of expressing what their pain felt like. They then had the opportunity of showing me the final images and discussing the result.

I had at some point in the planning stage thought that the process may open diagnostic avenues, but I rapidly came to realise that this was a minor and temporary atavistic aberration of Cartesian thinking: Virchow has little place in chronic pain management. Here diagnosis is not the only end point. Listening and acknowledgement are fundamental. To paraphrase John Major: perhaps there are times when we need to understand less and accept more.

The resultant images are extraordinary, moving and provocative. One fundamental question – could an artist develop images that had a meaning for the sufferer – was answered early on: some subjects still report a quickening of the pulse when they see 'their' images. The resultant exhibition, shown at St Thomas' and Guy's throughout May and June and

followed by a stretch at the Royal College of Physicians, reaffirmed the effect that these remarkable images have on the interested bystander. The feedback has been uniformly positive, not in terms of the beauty of the images, although many do have a strange aesthetic quality; but in their impact. We will long remember the medical student who wrote 'Thank you. I will now see chronic pain in a different light.'

For me the crucial aspect is the transference of the reality of experience. The sufferer stands brazen in front of an image of their disquiet one metre high. We cannot ignore it or walk away, it has gained a reality that has to be faced. Our confusion may remain but it is the subject who now has the strength and certainty. It is the physician who has to accept the premise, process the implications and respond. We have to take the representation as we find it; we can no longer disbelieve. It is humbling.

## Believing is seeing

### Deborah Padfield

*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*<sup>1</sup>)

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 unremitting 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

**Deborah Padfield**  
Visual Artist

*Clin Med JRCPL*  
2002;2:571-3