‘I feel as if everything is coming apart’: how images can change the dynamics of pain consultations

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In a London NHS pain clinic, a patient (whom we will call Sarah) is handing the clinician a series of cards, one by one. Each of the cards carries an image that was co-created by artist Deborah Padfield and chronic pain patients to help represent each individual’s experience of pain. While she was waiting for her consultation, Sarah took up the opportunity to select from a much larger set a small number of cards to take into the consultation with her. One of the cards is reproduced in Figure 1. As Sarah hands it to the clinician, the following interaction takes place:

> *Sarah:* *Um this has to do with my self-identity…*
> *Clinician:* *Ah, okay.*
> *Sarah:* *… being worn away by always having to pain manage and knowing that I have an achy time.*
> *Clinician:* *What about that one makes you think about your self-identity?*
> *Sarah:* *Because that person’s face is burning off.*
> *Clinician:* *Right, okay.*
> *Patient:* *So for me that’s self-identity.*
> *Clinician*: *That’s interesting, actually, because, um, I did some work with, I think it was her* [points at the card]*, um, when doing this project, so it helps me identify with that as well.*

The image in Figure 1 could be interpreted in multiple ways. Sarah uses it to disclose a sensitive and emotional aspect of the impact of the pain on her life: a sense of gradual loss of self-identity. The clinician provides back-channelling feedback throughout (e.g. ‘Ah, okay’), asks for clarification, and then explains that her involvement with the previous phase of the project helps her ‘identify’ with what Sarah is saying.

This kind of open, rich, empathic interaction about pain and its consequences is not easy to achieve. There are many reasons for this. Time is short. The use of technology means that clinicians may spend more time looking at a screen than at the patient. Patients with chronic pain often find it difficult to express fully the character of their pain, and the impact of the pain on their own and others' lives.

Clinicians, meanwhile, spend less and less time gathering the patient's history, and may not sufficiently value the personal stories that patients tell, or know how to respond to them. Yet, sensitive, successful interactions between patients and healthcare professionals do not just boost morale and general well-being, but can also contribute to diagnosis and to the identification of the most appropriate approach to care.

The extract we have quoted from Sarah's consultation seems to suggest that the pain cards open up opportunities for expressing and acknowledging the emotional impact of chronic pain. Sarah is confident and articulate throughout the consultation, but she seems to take more control and engage in greater emotional disclosure when she spells out her reasons for choosing each of the cards. Does this happen with other patients too? Is there any systematic evidence that the cards actually make a difference to the nature of the consultations? And, if so, what difference do they make?

We followed 10 pain clinicians and studied 17 consultations involving the pain cards and 21 consultations without them; each clinician was involved in both types of consultation. In the consultations involving the cards, we compared the parts of the interactions in which the cards were actively being used to the parts in which they were not used. As we first reported at the international conference 'Encountering Pain, Hearing: Seeing: Speaking' (July 2016, University College London), this revealed systematic differences in both verbal and non-verbal behaviour that suggest that the cards can make a difference.

When using the cards, patients speak more. Sarah and her clinician, for example, speak roughly similar numbers of words when the cards are not being used. However, when the cards are brought into the interaction, Sarah speaks four times as much as the clinician. This applies widely: all patients speak proportionately more when they are using the cards, and several speak more than the clinicians in absolute terms at those points in the interactions. In contrast, when the cards are not being used, or when they are not part of the consultations at all, the clinicians speak more than the patients.

Is there anything different about the language that is used around the cards? A computer-aided linguistic analysis suggests that there is. For example, patients use words such as ‘feel’ and ‘feeling’ much more often when they are talking around the cards. And those words are not just used to explain the quality of their pain (as in a ‘tight feeling just by my neck’) but also to reveal the emotional impact of the pain, as in:

> *‘Yes, I mean, literally I felt suicidal.’*
>
> *‘I feel as if everything is coming apart’*
>
> *‘I feel lost, I don’t know what to do.’*
>
> *‘Sometimes I feel a gap between my family.’*

Clinicians, on the other hand, also use words such as ‘feel’ much more frequently around the cards, but, not surprisingly, they use them to validate or enquire about the patient’s experiences, including both physical sensations and emotions:

> *‘This is about how you feel frustrated and tense, yes?’*
>
> *‘A wave that you feel was going to pass.’*
>
> *‘You feel lost, or loss?’*
>
> *‘So you feel a gap between, so you feel this, this generation gap yeah?’*

Clinicians also use words that express positive evaluation much more frequently around the cards, in response to patients’ explanations about the significance of the cards (e.g. ‘interesting’).

Parallel changes emerge from an analysis of non-verbal behaviour. Clinicians showed more positive affiliation behaviours when the cards were available, particularly in interactions around the cards: leaning towards the patient (and cards), smiling, nodding, "uh-huh"-ing, and using a relatively higher pitched vocal tone that communicates warmth and agreement.

Positive (or negative) affiliation behaviours tend to be matched by the interaction partner, eliciting the same behaviour. While the frequency of patients' affiliative behaviours was not affected by the cards, clinicians displayed affiliative behaviours more frequently and more markedly when the cards were available, and particularly when they were actively being used. For example, Sarah's clinician moves her chair several inches towards her when the cards are brought into the interaction, and holds each of the cards in turn. The clinician in Figure 2 similarly touches one of the cards that the patient has laid on her desk. The Figure also shows how the presence of the cards on the clinician's desk reduces the physical distance between clinician and patient.

Clinicians' behaviour also mirrors patients' behaviour more when the cards are in use, resulting in greater reciprocity. Unexpectedly, it was clinicians who showed more behavioural change when the images were used. This makes us wonder whether the difficulties in rapport in medical consultations, so often reported by people with pain, are less a sign that patients fail to communicate their experience of pain and more an indicator that the clinician is inadequately engaging with the patient's verbal account. While images help patients provide a fuller emotional account of the patient's pain experience, they may also elicit a more empathic hearing by the clinician.

Our observations of verbal and non-verbal behaviour lead to similar conclusions. Overall, the pain cards seem to change the dynamics of the consultation in multiple and subtle ways. When using the cards, patients have more control of the interaction and disclose more personal details about their experiences, especially with respect to the emotional impact of pain on their lives. For their part, clinicians provide more positive feedback, verbally and non-verbally, and behave in ways that suggest a closer and more equal relationship.

All of this provides both opportunities and challenges for the future. Can the cards truly lead to a more collaborative relationship in which patients gain more knowledge to help them understand their illness? Could the cards help patients become more active and involved in decision-making? Could the cards be particularly useful for patients who have language difficulties? Could the cards increase patients' adherence to treatment plans by improving rapport and increasing trust? Do clinicians have the resources, including time, to deal with greater disclosure about the impact of the pain on the patient's life and emotions? What kind of support and training would be needed, for both patients and clinicians, to make sure that the cards' potential is fully realised? Addressing these questions will make it possible for the pain cards to become a powerful tool for the future of pain consultations.

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Further readings:

Biro D. *The Language of Pain*. New York: W.W. Norton & Company Inc, 2010.

Bourke J. *The Story of Pain From prayer to painkillers*. Oxford: Oxford University Press, 2014.

Charon R. *Narrative Medicine. Honoring the stories of illness*. Oxford: Oxford University Press, 2006.

Deignan, A., Littlemore, J. and Semino, E. *Figurative Language, Genre and Register*. Cambridge: Cambridge University Press (chapter 9), 2013.

Padfield D. 'Representing the 'pain of others' in Bell S. & Radley A. (eds) Another way of knowing; Art, disease and illness. *Health* 2011;15(3):241-258.

Legends:

Fig 1: Deborah Padfield with Nell Keddie from the series *perceptions of pain 2001 -2006,* Silver Gelatin Print

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Fig 2: Recorded consultation 'silhouettes' to show non verbal relations