

## Are we being patientist?

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**Doctors, nurses and health professionals allied to medicine** are mainly trained in a traditional unidimensional approach to patients and their problems. Physiotherapists' training does emphasise a rehabilitation approach, yet this originally had its roots in unidimensionalism where the doctor/therapist was the expert dispensing wisdom and advice. Importantly, even when as physiotherapists we begin to use a more multidimensional and biopsychosocial approach to our patients, it is still very hard to throw off what we learnt so well.

We need to be aware of factors in the traditional approach to chronic pain that encourage a single construct model of pain, or that take autonomy away from the patient. Some of the traditional terminology we might use can not only lead us back to thinking unidimensionally, but can also, in or out of context, encourage prejudiced or 'patientist' thinking. It is the use of terms or labels in relation to patients with chronic pain that is the focus of this chapter.

Psychiatry's approach to chronic pain arose from a more medical approach to illness (Gamsa, 1994). Black (1975) called it the "Chronic Pain Syndrome" relating it to patients with "no clear organic pathology, only symptoms". He was thus implying that if pain is not physical then it must be mental. This had developed from Psychiatry's psychosomatic school where physical symptoms are said to be produced by psychological factors e.g. asthma is separation anxiety.

This has not yet been proven conclusively, and the movement in chronic pain is now more towards physical illness *maintained* or made *more problematical* by psychological factors. Psychiatrists have still tended though, to see things in terms of pain due to psychological mechanisms, and try to find explanations that are purely psychological. Black for example refers to 'no physical findings', yet admits that this depends on modern technology and where you look.

I think this is a warning to us to be careful in the way we think and speak about patients with chronic pain. We may be utterly convinced that all pain has a physical component as well as psychological and social components, and be only too well aware of the limitations of medical diagnosis.

If however, we use phrases like "no physical findings", "symptoms out of proportion to the injury" or "inappropriate signs", it will not be too long before patients hear us say this, read it in a letter or hear it repeated second hand from a colleague. They can then quite rightly feel angry at our betrayal, feel misunderstood, and realise that we have our colours pinned to a different mast than we are espousing. Importantly, it will affect our approach to patients even if this appears quite minor initially. It is an indication that there is a mismatch between our actions and our understanding of the biopsychosocial approach. It indicates that fault or blame are creeping into our view rather than degrees of responsibility based on a wider view of a patient's difficulties.

### Patients' past experiences

Patients have had to contend with many disbelieving and blaming health professionals in the past. These professionals may have stated as well as implied that pain is in the patient's mind, may have indicated irritation when the patient is not able to 'comply' with instructions exactly, and may have had a 'pull yourself together' tone of voice at times. When patients have past experience of this, it inevitably leads to heightened sensitivity and defensiveness for these attitudes. If patients think you are being judgmental they will hear that message rather than the message you want them to hear. We need to be extremely careful that we do not use words, phrases or tone of voice that could in any way indicate a digression from the wider biopsychosocial model. If not, this makes it much harder to work with the patient and tends to break what therapeutic alliance has existed until then.

## Terms that may provoke misunderstandings

The term '**somatisers**' appears in the psychological as well as psychiatric literature, and is also being used in the biopsychosocial approach to chronic pain and illness. However, the label of somatiser is generally derogatory, and implies an individual who 'complains' a lot, makes a fuss, seems weak willed and easily frightened, dwelling on illness and fears, and blames them for 'needlessly focusing on ordinary symptoms' rather than 'pulling themselves together' and getting on with life.

Equally, since people are aware of the futility of telling someone to stop focusing on symptoms, it is easy to see how a therapist might feel helpless or even irritable in the face of these images. Certain patients may then be seen as the link to or cause of these feelings. If however, we look at the wider picture and gain a better understanding of the mechanisms involved, this now presents a picture whereby these patients are seen to be behaving quite logically or normally considering their beliefs about their illness and their past and present circumstances. Also, and importantly, it suggests the means to changing the way patients manage their situations - both in terms of their behaviour and their cognitions - so that they gain control over them.

Other words we use also need to be used with care. Cognitive-behavioural (C-B) pain management has its own jargon that can be easily misconstrued, and it may well be preferable to use and become familiar with less emotionally-loaded terms.

**Conditioning:** Operant conditioning is a term used in C-B pain management that describes the method of observing and influencing reinforcement of behaviours that patients have, in order to help them make changes. Conditioning however can be associated with training rats in a laboratory or seem like tricking people or manipulating them. **Learning** is a more helpful and jargon-free term. Operant learning can be used in place of operant conditioning, and its use indicates that the user is familiar with the practical application of operant techniques in a value-free patient-orientated way (Harding 1998).

**Behaviour:** This word is usually associated with bad behaviour, and in chronic pain, with unwanted behaviours - 'pain behaviours'. Any behaviour however has a context in which it is appropriate. Pain behaviour can be completely appropriate in acute pain. **Habit** is a much less loaded word - everybody has them, good and bad. We also all know that habits are not easy to break. If the word habit is used patients will possibly accept more readily that their therapist's expectations for change are not set unrealistically high. They will then be less likely to feel under pressure.

**Avoidance** and, to a degree, **fear** need to be used with care. Avoidance can sound like something the patient is blamed for - 'brave' people don't do it - just like fear is only for wimps. There may be no direct alternative so we should perhaps be aware that other professionals need to know what we mean, and preferably not use the term in front of patients - they rarely after all *completely* avoid anything at all times - 'tend to avoid' would be more accurate and the word can be avoided altogether: less active rather than avoid activity; has much reduced weight bearing rather than avoids weight bearing etc. Fear is a word that really needs to come from the patient. If you are helping patients to recognise the feelings associated with certain situations or cognitions, 'apprehension' or 'concern' may be kinder. Wait until patients use the word fear before you adopt it in relation to them.

Patients sometimes use the terms **positive thinking** and **negative thinking**, particularly those who may have heard of the book "The power of positive thinking". Occasionally these terms have crept into the physiotherapy literature. We perhaps need to remind ourselves that these terms are very simplistic,

and imply that all one has to do is 'think positive'. This does not recognise the difficulties patients can have with complex cognitive issues, and the potential futility of just 'thinking positive'.

Positive thinking can quite easily feel hollow and empty and unable to meaningfully challenge those thoughts that are responsible for anger, distress or low mood. Some circumstances can be inherently without a positive dimension. Patients could get very frustrated or distressed by trying to pursue positive thoughts about their husband dying or about having chronic pain for the rest of their lives.

If 'negative thinking' is considered bad, then avoiding it may prevent patients from addressing what is difficult or painful for them, much of it based on all too evident reality. More useful terms to use are **helpful** and **unhelpful** cognitions or thoughts. These terms are not loaded, and will tend to lead patients towards useful coping self-statements and problem-solving rather than just mantras.

'Active' and 'passive' coping strategies are terms that are found in the pain management literature, but are possibly not helpful and should be used with great care. The words active and passive again can be quite loaded or judgmental. Rest for example can be termed a 'passive' coping strategy, yet is a vital part of pacing provided it is not too long and reinforces activity. Like cognitions, coping strategies perhaps need to be deemed **helpful** or **effective** versus **unhelpful**. This allows one person's unhelpful coping strategy to be another's helpful coping strategy, based on their pathology and circumstances, and not on something good or bad.

Emphases need to be watched too. Try not to indulge in 'Musturbation'! 'Shoulds' and 'musts' 'must' not creep into our language. Since we wish patients to gain control "patients may...." is usually more appropriate than "patients should....". We need to recognise that patients are different and do not readily fall into uniform groups.

We also need to watch that any of our preconceived ideas don't influence our view of patients. Patients for instance can be happy in certain types of relationships that research indicates may increase the likelihood of dependence or disability. It is not up to us to rock the boat or make assumptions, merely to help patients try things out, look at the evidence and their options, and make their own informed choices.

The behavioural approach aims to help patients cope better under difficult circumstances. It does not aim to make people more stoical - this is in fact often counterproductive since patients can easily come unstuck if they try to ignore the pain and battle on. It often leads to increased physical tension which causes deterioration in movement and function, and can result in a cognitive backwards step: "I knew I couldn't manage it, I'll never get any better" "it's all in my mind" or "it's mind over matter".

**Pain complaints** and **complaining** are words that tend to sound judgmental or what we don't want to hear: "stop complaining, just put up with it" i.e. be more stoical.

### **Why pain behaviour might appear to be 'inconsistent'**

'Inconsistent Pain Behaviour' is a phrase that is sometimes used, and which can imply that the patient's symptoms are not genuine and therefore blameworthy. It is thus good C-B practice to look at what is happening and how this can be interpreted:

- Pain behaviour varies in response to the same stimulus - many stimuli are present, that stimulus might be the only one remaining the same
- Behaviour varies in different settings - this indicates the complexity of chronic pain and the many and varied cues and reinforcers operating, usually at unconscious levels

- Behaviour inconsistent with statement about behaviour: "I can't..." when a patient is able to partly do something. There are degrees of "can" as well as "can't". We may be looking at the degrees of can while some people only rate can when it is perfect. Addressing or arguing with patients about "can't" may be unhelpful until they can recognise the benefit of looking at the degrees of can.

Patients' pain behaviour can be reinforced by others, however it is worth looking at hypotheses for other reasons for 'variation in pain behaviour':

- Good day / bad day / time of day - these will all influence parameters such as pain, stiffness and tiredness that affect movement and behaviour directly.
- Have we correctly identified the stimulus and the meaning?
- You suspect faking? People with no pain can fake a limp, but it is hard to maintain for long, as concentration turns to other activities. A patient with a long established limp will maintain that limp long past their (or anyone else's) concentration span, indicating that non-conscious mechanisms are involved. The notion that someone is consciously controlling or 'faking' a limp across all contexts and across time is far fetched.
- Distress/emotions - during times of increased anxiety or lower mood, patients' ability to cope is reduced. This may influence behaviour relating to pain.
- Gradual extinction of behaviour - while behaviours are undergoing extinction there will be increases and decreases in frequency and strength of those behaviours in response to the intermittency or extinction of reinforcement (Harding 1998)
- Secondary gain - this implies deliberate manipulation to get something from another. This may of course be the case, but usually occurs when patients do not appear to have other, more worthwhile, options. Perhaps rather than looking at secondary gain it is helpful to see if this could be re-framed as secondary loss, i.e. the patient is behaving in this way as a result of having lost important skills or opportunities. Then the patient can be helped to see if perhaps there are other options that would be more valuable. If there are not, perhaps their response could be judged to be reasonable and fair given their present circumstances - not an impression given by use of the term secondary gain.

Some of these hypotheses are likely to be operating with an individual, some not, and some should be rejected even if they are held by others.

### **Hypotheses testing**

Hypothesis testing is a useful exercise to do for the hunches we have about our patients' behaviours. There are several ways to do this:

- Observe - more careful and lengthier observation of cues, behaviours and reinforcers may help us confirm or disconfirm our hypotheses.
- Monitor details of the situation - it is sometimes necessary to actually measure frequency and timing in order to uncover which cues and reinforcers are most powerful.

- Ask - asking the patient is empowering, though choosing the right question is important. It is vital to avoid the implication that you are trying to catch them out, since patients will likely have been sensitized to this by professionals or relatives in the past.
- Provide feedback - discussing your observations with the patient, provided again you avoid the implication that you have been trying to catch him/her out. Use of words like habit are very useful here, as is evidence that others are responding this way too, so that the patient is not made to feel unusual or stupid.
- Experiment with contingencies. It is very difficult to be consistent with providing cues and reinforcers which may be why behaviour appears to be inconsistent. Experimenting can help clarify the situation.
- Video and private detective. If it is your aim to catch the patient out and try to prove dishonesty, this method may seem appropriate. However it is expensive, unethical, and more importantly not valid, since it is only a snapshot of a short period of time and does not record any of the other contingents operating (see above), pacing and pain level.
- Research findings can be turned to for elucidation however these are based on group data and group trends, and not on the individual. Group data should merely guide some of the content or emphases of group pain management. Its relevance to the individual needs to be established separately every time.

Finally, it is worth considering if *any* behaviour is consistent, and why we should expect patients' pain behaviour to be consistent when our own behaviour is variable. Just as Salkovskis (1996) states "...there is no place in the [cognitive] theory or the therapy for the idea of the therapist defined "wrong thinking", which is inappropriately judgmental...", so it should be also for habits or behaviours.

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