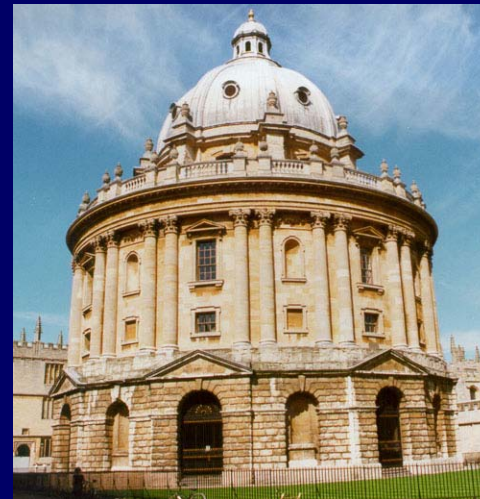


Patients' understanding of jargon and common medical terms.

- *Karen Barker PhD
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Physiotherapy
Research Unit
Nuffield Orthopaedic
Centre NHS Trust
Oxford.*





Background

Previous research¹ suggests that the language used to define, describe and discuss low back pain has different meanings for patients, members of the public and primary health care professionals.

¹Barker, Minns Lowe and Reid (*Manual Therapy* 2007, 12 :335-341)



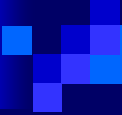
Objective

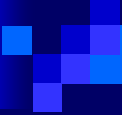
The aim of the research was to identify and explore the meanings of some commonly used medical terms for pain from the perspective of

1. primary health care professionals (hcps)
2. members of the public who have and have not seen a health care professional (nhcps).

Method

- Design: a qualitative study using 9 focus groups (facilitated by social scientist)
- Setting: convenient community and health care locations in England, UK
- Purposive sampling (n=66 participants): 9 groups included General Practitioners, Osteopaths and Physiotherapists. Non-healthcare professions –those who have and have not experienced musculoskeletal pain & different gender & socio-economic groups.

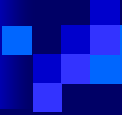
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- The sampling frame for lay participants included men and women, a broad spread of socio economic groupings and ages and those with and without experience of MSK pain.
 - All those with experience of pain had sought professional help. Fifty percent of C2DE Socio Economic Group Members had manual occupations.
 - Non English speakers were excluded.
 - All health professionals worked in Birmingham or the West Midlands region and all lay participants lived in the West Midlands

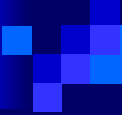
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- All focus groups were lead by MR, an independent professional qualitative researcher. A list of medical terms was presented individually; verbally and also written on cards.
 - Terms were identified from multiple sources including journals, textbooks and local copies of medical correspondence provided to patients
 - The list of terms was used in reverse order in four groups to minimise order effects.



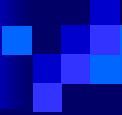
Data Analysis

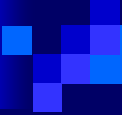
- Audiotapes were fully transcribed
- Line by line analysis using constant comparison
- Concepts and properties were identified
- Data was coded to describe and relate categories and subcategories
- Data analysis independently undertaken by two authors.

- 
- Healthcare professionals claim an active and important role in explaining terminology which patients bring to them from other consultations or, increasingly, have found on the internet.

- 
- *...I'm certainly finding (patients) spend a lot of time looking things up on the internet and they come back with all these big complicated word they don't understand. It becomes our role because we have about half an hour with them to actually explain these things to them to calm them down.*

(Physiotherapist)

- 
- Healthcare professionals report that it is often the patient who introduces terminology at consultation - sometimes accurately and sometimes not – in particular terms which are descriptive of symptoms.

- 
- *...you're asking us to talk about how we handle the language as symptomatic; its presenting and describing the symptoms language which 80% or 90% is coming from the patient.*
 - *We're listening; we're at the receiving end.*
 - (GPs)

Results: 3 themes





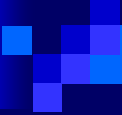
Results – Themes

1. “Red light” terms: Misunderstood / misconstrued terms which could lead to problematic misunderstandings
2. “Amber light” terms: Terms with unintended meanings but with few negative repercussions
3. “Green light” terms: terms understood as health professionals intended.



Wear and tear



- 
- *Wear and tear makes me think that something's actually diminishing. So, like a bone is getting thinner or a muscle is wearing thinner. It's shrinkage and it's unnatural. So that's what I think of wear and tear – something's rotting away.* (Male, C2DE, 20-39, with pain)
 - *It's not very nice when you hear it because you know you're getting older and you know it's going to get worse and you say "Oh, is this it now?".* (Female ABC1, 40-59, no pain)

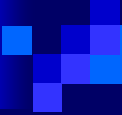
- 
- *It's expected. You're wearing out.*


(Female, ABC1, 40-60, with pain)

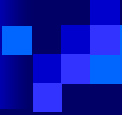
- *No I wouldn't necessarily say age...I think it might just be you've got one of those things. Like with arthritis it never gets better, it just gets worse.*

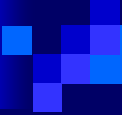
- (Females, C2DE, 20-39, no pain)

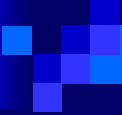
- 
- **There were two very different emotional responses to a *wear and tear* ‘diagnosis’**

- 
- Some claim they would be or indeed were relieved that their pain in being wear and tear was not something more serious.
 - *I'd feel relieved actually.*
 - *...Relieved it's nothing. I haven't got too bad, there's totally nothing wrong with me.*
 - *What you expect at the age you are.*
 - (Females, C2DE, 20-39, no pain)

- 
- However, the majority of respondents in the general public sample reported this diagnosis of wear and tear would leave them feeling:

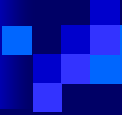
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- *Depressed – I'm getting old (before my time).*
 - *There's no treatment, I have to put up with this for the rest of my life*
 - *It can only get worse.*
 - *As if they were being fobbed off for wasting the doctor's time – and this is considered insulting.*
 - *Disappointed when they were looking for an answer and treatment.*
 - *It does not seem to acknowledge the pain.*

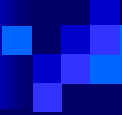
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- *It's like they're taking the p***...Doctor sits there "Oh, it's just wear and tear."*
 - *...It's quite condescending really isn't it when they say that?*
 - *Especially when you're suffering.*
 - *(Females, ABC1, 40-60, with pain)*

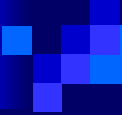
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- HCPs use *wear and tear* though some insist it be accompanied by an explanation of how *wear and tear* or *arthritis* is not necessarily serious and that something can be done.
 - *They're almost waving the white flag and saying oh that's it I'm old now and I've got to accept a lot of aches and pains and this is just normal wear and tear this is how I'm going to be for the rest of my life.*

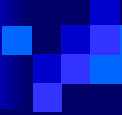


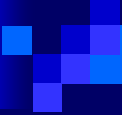
Arthritis

- 
- *Inflammation.*
 - *It's crystallisation, isn't it...What's it called that gooey stuff that sponges the joints so say if you've got a ball and socket joint and it's the gunge in the middle. That disappears. It crystallises.*
 - (Females, ABC1, 40-60, with pain)


- 
- - It is also considered incurable and by that some seem to mean untreatable - and steadily gets worse.

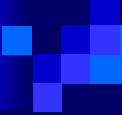
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- *...it'll get worse...you're diagnosed with that as you get older it's going to get worse and more painful...*
 - *There's not a lot of treatment for it that works.*
 - *(Females, ABC1, 40-60, with pain)*

- 
- *Arthritis sounds like it's ill health and it's serious and a bit of wear and tear sounds just like living on this planet and normal and everybody in the room's got a bit. If somebody comes in and says they've got arthritis they're usually a bit more worried about it.....I avoid the word. Physio*



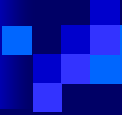
Acute

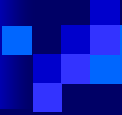
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- To lay people / patients used quantitatively to describe the magnitude of pain
 - *“It’s acute, it’s sharp, it’s intense,*

- 
- *I think patients if they go “Oh I’ve got acute back pain” they think it’s like a quantifying factor ...that’s why I don’t tend to use it because ... it’s incorrect language....It’s a temporal thing rather than a qualitative.*
 - (GPs)



Chronic

- 
- Health professionals are aware that the general public tend to interpret *chronic* as severe and sometimes unduly negative i.e. “incurable.”
 - *It means long-term, long-standing. Ongoing. yeah. Whereas colloquially people use it - I don't know whether it's just Birmingham – but “I've got the most chronic pain”.*
 - *...Severe. To them chronic means severe.*
 - (GPs)

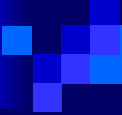
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- *Severe, chronic terrible pain.*
 - *Chronic means absolute, the pits.*

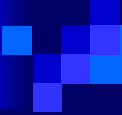
(Male, C2DE, 40-60, with pain)

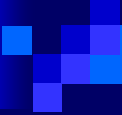
- *Perhaps even: Couple of steps from a wheelchair.*

(Male, ABC1, 20-39, no pain)

- *It can suggest incurable to some.*
- *It implies again something that's...going to be there forever.*

- 
- *I don't use it that much because again it's like degenerative; it's unfair with "Is this it?" Am I going to be stuck with this?"*
 - *It's scary*
 - (Osteopaths)

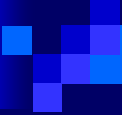
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- Most HPs prefer to use phrases such as *long-term, long-standing* and *ongoing* as simpler alternatives.
 - *I think long-term is just a simpler word to use and it's something they will pick up on straightaway...*
 - (Chiropractor)

- 
- The physiotherapists tended only to write and not say *chronic*. They recognise the different interpretations by patients.
 - *It's a horrible word (chronic). I don't say it much to patients; I write it down in my notes.*
 - *...I think there are two definitions actually. One is comparing it with acute – in fact acute is like a thunderstorm if you like and chronic is like it's raining for a long time. But the patients, the elderly patients particularly often use the word chronic as something which is absolutely bloody awful.*

Self Management

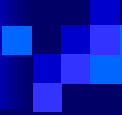


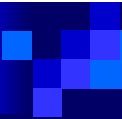
Picture from Google Images

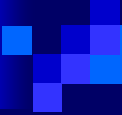
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- *I'd feel a bit left on my own in the cold if the doctor said that to me. "I'll tell you how to manage your pain." I would think well you're not interested are you?*
 - *Or there's nothing you can do about it.*
 - *...You've got to manage.*
 - (Female, C2DE, 20-39, no pain)

MRI Scan

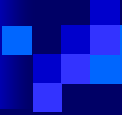


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- A few respondents believe an MRI is a brain scan.
 - *That's a brain scan.* (Female, ABC1, 40-60, with pain)
 - *I thought it was brain...It's everything.*(Males, ABC1, 20-39, no lbp)
 - In one group MRIs were associated with cancer.
 - *...MRI in connection with cancer. Yes I think it's more serious if you're told you've got to have an MRI.*
(Females, C2DE, 20-39,)



- 
- *One muscle's bigger than the other. One of them's wasted away and the other one's working double time.*

(Males, C2DE, 40-60, with no pain)

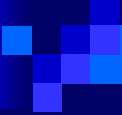
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- *I use weakness if you're talking about physio, muscle strengthening exercises and that sort of thing; not very often though.*
 - *...But the weakness might imply permanent.*
 - *It doesn't mean you're a weak person.*
 - *No I wouldn't go there.*
 - (GPs)

Exercise

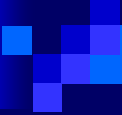


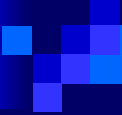
Activity




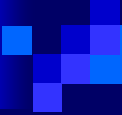
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- These have quite distinct meanings for the public. *Exercise is a specific thing for a specific area maybe. Activity is just general, keep yourself busy.*
 - *Exercise is always planned as opposed to activity (which is) just normal movement.*

(Female, C2DE, 20-39, No lbp)

- 
- Some HPs use general exercise and general activity interchangeably. Others, recognise the distinction made by the public.
 - *You could use general exercise or general activity it means more or less the same thing.*
 - *It depends on the patient's response because some patients you say exercise and you can see that awful look of horror on their face.*
 - *They have visions of you sending them off on circuit training.*
 - *(Physiotherapists)*

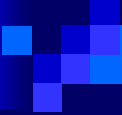
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- More acceptable phrases than exercise for respondents across the sample were 'keep moving', 'stay active' and variations on these.
 - *I think the gentle exercise one implies that you have got to go and do something whereas with the active (one) you are just being active, just keep moving, you don't have to do anything special.*
 - (Male, 40-60, ABC1,

- 
- Suggesting 'exercise' could in fact provoke a degree of resentment rather than reassurance among those who do keep active with pain, with respondents indicating that their work or looking after a family provided more than enough exercise without having to do more.

- 
- *That might apply to some people but generally if you're working and looking after kids you can't do that. ...by the time you've finished at the end of the day you're aching and the last thing you're going to want to do is gentle exercise. You've already overdone it in the daytime.*

(Female, 20-39, ABC1,

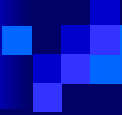




Muscle spasm

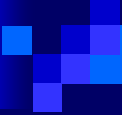
Rehabilitation

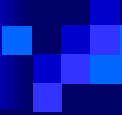


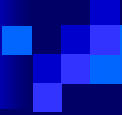
- 
- *Trying to get back to normality* (Male, C2DE, 20-39, with pain)
Well it's the recuperation. It heals. (Female, ABC1, 40-60, with pain)
 - *Someone's getting you back to where you were.* (Male, C2DE, 40-60, no pain)
 - But it also sounds very positive to the public. *That sounds good because there's ...light at the end of the tunnel. ...You're on the road to recovery.* (Males, ABC1, 20-39, no pain).
 - *We use rehabilitation because it is forward looking... ...Restoring normality hopefully.* (Physiotherapist)

Results – Overview

- Commonly used terms by all professionals have unintended meanings
- Patients/ex-patients have some greater insight into very specific terms
- Areas and levels of understanding or misconception are similar between these members of the public with and without experience of pain
- Professionals were sensitive to problematic terms, employing strategies to avoid/explain them. Each profession specific group in this study favoured certain terms, and were providing different explanations to patients.

- 
- Professionals in primary health care who were interviewed seem sensitive to terms and phrases used in discussing pain with patients which might be misconstrued and lead to anxiety or worse in their patients.

- 
- *I think people's rate of recovery and their perception of how well they are is strongly affected by the language that we use. So you tend to make it kinder and gentler.*
 - *...I think patients do make assumptions...once they've heard that from you they think that's something I can't actually deal with or that's something that's going to take so long to correct I can't deal with it. So I try and use maybe more positive phrases that don't scare them.*

- 
- Consequently, health professionals (HCPs) claim a tendency to avoid these terms verbally though they do still tend to write some of them in notes for other HCPs.



Conclusion = NO!

- This preliminary, non generalisable, research indicates the presence of a large English language gap, between hcps and nhcps
- There were very few terms understood similarly by all groups
- Health professionals are sensitive to the problem and try to promote “insight without jargon”.

References



Available online at www.sciencedirect.com



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www.elsevier.com/locate/math

Original article

The development and use of mass media interventions for health-care messages about back pain: What do members of the public think?

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Research article

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Divided by a lack of common language? - a qualitative study exploring the use of language by health professionals treating back pain

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