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Successful Return to Work with Chronic Pain? Stakeholders’ Negotiation Strategies

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Is work good for us?

Despite sometimes feeling like this…

[image redacted]
Yes – for 90-95% of us! (Waddell and Burton, 2006)

- Review showing remaining in work/ returning to it beneficial for MSD patients (Waddell and Burton, 2006)

- Trans-generational effects of worklessness
  Black (2008); Black and Frost (2011)

- Early RTW interventions – no higher risk of recurrence/ increased sick leave (McCluskey et al., 2006)
Proportion of working age population in receipt of Incapacity Benefit

[image redacted]
Government policy to reduce sick leave

- SL can be appropriate but can extend sick role unnecessarily (Waddell and Burton, 2004; Black, 2008)
- From “sick note” to “fit note” in 2010 (electronic version 2012/13)
- 4 new options – phased return, altered hours, amended duties, workplace adaptations
- “may be” or “not fit”
- DWP national education programme for stakeholders using EBM (e.g. via RCGP)
Proportion of working age population in receipt of Incapacity Benefit
Chronic pain

• Chronic pain: ‘unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage’ (IASP, 1986)

• ‘Intractable pain that fails to respond to treatment’ (Waddell, 2004b)

• Complex and dynamic (Von Korff and Miglioretti, 2005)
Sickness certification for chronic pain patients: conflict and negotiation

• Lack of observable pathology; essentially contestable (Wainwright et al., 2006; 2014) sick role (Parsons, 1951) stigma (Goffman, 1968b)

• Sick role (Parsons, 1951): patient can temporarily withdraw from social roles as along as seeks legitimate help

• GPs’ legitimacy and right to practise depends on state (Doyal, 1979)

• GPs must balance patients’ best interests and gatekeeping (Hussey, 2004)

• GPs sick-list (almost) daily: cause of challenge and contention (Wynne-Jones et al., 2010)
• LBP patients actively seek sick notes (SR, Verbeek et al., 2004)

• Occurs “on demand” to avoid conflict (Hussey et al., 2004) “You feel so helpless” (Chew-Graham and May, 1999)

• Cultural norm of sympathy; what if patient falls into the 5-10% for whom work = worse health outcomes? (Wilkinson, 2005; Wainwright et al., 2006)

• Yet: LBP patients frustrated by GPs who rush to sick list (Coole et al., 2010)
RQ: How will the fit note and education programme initiatives affect GP-patient relationships?

• What about existing tension between GP as patient advocate and gatekeeper?

• Special problem for MUS/pain in which prognosis, diagnosis and work capacity can be unclear

Aim (Wainwright et al 2014):

• Investigate the experiences of negotiating medical certification for work absence

• Explore patients’ and doctors’ views of new policies
Research design: ontological issues

- Qualitative study; suitable as enables in-depth exploration of macro/micro entities
- Notions of acceptable absence and tolerable pain seen as socially constructed
- Symbolic interactionism: purpose of social science to understand cause of human action; we can start to understand this if we understand what actors believe about their world
Research design: epistemological issues

- Reconstruct actors’ realities, via interview, including asking them for retrospective accounts of their actions (Charon, 1992)

- Truth as construction:
  - Habitus of sociology promotes intellectual bias (Bourdieu, 1990)
  - “Truth” rooted in historical conditions of possibility: what we know structures reality into concrete experiences (Foucault, 1984c; Greco, 1998)
Methods: Constructivist Grounded Theory

- Grounded theory – provision of categories of processes to help understand assumptions (Glaser and Strauss, 1967; Strauss and Corbin, 1998)
- Provisional open coding – “What is CP?”
- Exploration – attributes of “fluctuates” and “something to limit”
- Re-categorisation into analytical concepts “shattered self” and “stigma”
- Axial coding – identity as person/as pain patient
- Deviant cases “Pain makes me stronger”
- Bias reduction – attempt, be transparent, ack. tension
Methods

- Qualitative study; suitable as enables in-depth exploration of macro/micro entities
- Notions of acceptable absence and tolerable pain seen as socially constructed
- Semi-structured face-to-face and phone interviews (Denzin and Lincoln, 1994)
- \( n = 43 \) (30 patients; 13 GPs) until saturation (Glaser and Strauss, 1967: Guest et al., 2006)
- Constructivist grounded theory (initial and focused thematic coding) (Charmaz, 2006)
- NHS and UoB ethical approval
## Patients

| Gender                        | F = 24  
|-------------------------------|---------
|                               | M = 6   |
| Works full-time, part-time, or does not work (no W) | W FT= 15 
|                               | W PT = 5  
|                               | No W = 10 |
| Years suffering from pain*    | Mean = 8.03 
|                               | Median = 7  
|                               | Range = 1-20 |
| Conditions participants described suffering from (some had multiple morbidities) | Undiagnosed = 3 
|                               | Fibromyalgia = 6  
|                               | General back pain = 6  
|                               | Lower back pain = 3  
|                               | Abdominal pain = 2  
|                               | Pelvic pain = 2  
|                               | Arthritis = 2  
|                               | Rheumatoid arthritis, osteo-arthritis, inflammatory arthritis, upper limb pain, CRPS, tennis elbow, DISH, Ehlers-Danos type 3, knee pain, RSI = 1 each |
| GPs          | Gender | F = 3  
|             |       | M = 10  
| Years practising* | Mean 21.61  
|             |       | Median 22  
|             |       | Range 12-26  
| Works full-time or part-time | FT = 9  
|             |       | PT = 4  
| Practice is rural (R), urban (U) or mixed (M) | R = 7  
|             |       | U = 6  
|             |       | M = 0  
| Pain management training | No training = 12  
|             |       | Diploma in Palliative Care and Diploma in Acupuncture = 1  
| OH training | No training = 9  
|             |       | Training = 4 (Diploma in OH)  
| Country of primary medical education | UK = 12  
|             |       | Australia = 1  


Three core themes:

1. GPs: double uncertainty of managing MUS and mapping these onto capacity. Some negotiated solutions.

2. Patients: struggle to achieve state-sanctioned legitimacy; enactment.

3. Conceptual agreement with WHW policies but problems applying this personally.
1. GPs: double uncertainty of managing MUS and mapping these onto capacity

- Building up experience of patients’ enactment, is how we benchmark the particular patient’s pain in front of us ... some patients hunch and guard and some have learned to accept [their pain] so it’s harder to gauge their level of pain. (GP 11)

- Medical authority? ‘In the end, it comes down to the patient, and some are not as eloquent as others’ (GP 8)

- Cannot simply deduce via signs and symptoms: GPs need to engage with patients’ illness narratives (Kleinman, 1988).
1. GPs: double uncertainty of managing MUS and mapping these onto capacity

- *It’s extremely difficult because you can’t see somebody’s pain. Quite often the patients just bounce into the surgery and don’t look like they’ve got pain at all ... they’re the problem ones. They say they’ve got agonising back pain and can’t possibly work, but there’s no objective evidence (GP 2)*

- *The trouble is, of course, as a GP, I don’t necessarily know much about their work (GP 6)*

- *Intellectual discomfort (GP 6)*
1. GPs: double uncertainty of managing MUS and mapping these onto capacity

- *There are some patients who basically have jobs that they didn’t like at the best of times ... that’s where the problem lies, the motivation to return is poor* (GP 9)

- *I’m not going to send them back if I think that will make them worse, whatever the DWP or anyone else says* (GP 4)

- *Withholding FN disrupts Parsonian roles so use “achievement” (GP 11) of note to restore habitus for both*
1. GPs: double uncertainty of managing MUS and mapping these onto capacity: solutions

- **TRUST**: I don’t think people set out to mislead us, it’s not in their interest (GP 13)

- Active listening

- Target set with patients (and/or send patients to “benefits doctor” (GP 13) to save GPs’ own relationship

- *It’s about managing expectations. I’d give shorter and shorter notes and I’d say in one consultation that the next note would be shorter, so I’m setting up that situation* (GP 10)

- Active process of (re)negotiation

- Contacting employers directly

- Improving PMPs

- Making working conditions better so GPs are less concerned about sending patients back
2. Patients: struggle to achieve state-sanctioned legitimacy

Presentation + fluctuation = delegitimisation:

- I must admit I’ve routinely made damn sure somebody does see me when my back is bad, because I think it’s just too easy to ... you know, to wait till you’re better and then go down the doctors’. I talk to fight, if you know what I mean. But then you realise underneath, actually I wish I wasn’t fighting (Patient 1)

- Enact symptom presentation to persuade:
  *Unfortunately the system makes people do that, you’ve got to demonstrate your worst days* (Patient 1)

- Risk: illness deception? Or patient feels fictional
2. Patients: struggle to achieve state-sanctioned legitimacy

Mutual process of scrutiny: GP surveys patient and patient surveys GP:

- *I didn’t like my GPs before – I just didn’t like the face that they pulled, like, ‘Oh, again’. They would do the note but I would leave their practice with a very guilty feeling and I was feeling like a criminal sometimes ... [the pain] was real ... I looked healthy, but it was true.* (Patient 6)
2. Patients: struggle to achieve state-sanctioned legitimacy

Further, mutual disruption of ideal roles away from supportive GP and resilience patient

- He’s written fibromyalgia down as well on it [the note], ticked ‘you may be fit for work taking account of the following advice’, then he’s ticked ‘amended duties’. Now that’s because when I went, he said, ‘Is it any better?’ I said, ‘From how it was, yes, but it isn’t right. It still keeps swelling up and everything else’. As you’re talking to him, it’s almost as if he just doesn’t want ... to listen ... it’s almost as if ... if you’re not committing suicide, he doesn’t want to know. If I sat there in floods of tears and was screaming and shouting and everything else, perhaps he’d take more notice. (Patient 20)
2. Patients: struggle to achieve state-sanctioned legitimacy

- Feel fraudulent even if enacting pain that “really” is present other times
- Feel stigmatised if refused SN (without perception of being listened to)
- Patients wanted their own accounts to be centralised but GPs experienced some discomfort here
3. Conceptual agreement with WHW policies but problems applying this personally

- All agreed in theory that “safe and accommodating” work (W & B, 2006) is good for us

BUT:

- Most of the time I think work can be therapeutic – it’s better to get back to work and be normal. But for some people, work is the issue, so then I write them a sick note. (GP 12)

- If people with chronic illnesses can be normal, it really helps; having a job is a normal thing to do ... [but] I’m soppy soft’ (GP 6).

- I’m currently managing to work full-time but at the complete expense of my social life. I’m always resting to recover from work and to ensure that I can work again the next day ... just wanted to make it clear that there’s a price to pay for determination to carry on! (Patient 19) Goffman covering
How can the FN and NEP help?

- Doctors want to change how patients conceptualise illness and respond to it.
- Do this not via reciting evidence base but by valued tacit skills of persuasion and negotiation, developed over practice.
- Policymakers/latest iteration of GP training recognises this.
How can the FN and NEP help?

- Can we further improve sick listing by developing these persuasion/communication skills even more?
- Any research on this? No – but some research since ours shows that not much has changed: “Advice was often incomplete or irrelevant” (Shiels et al., 2014; Coole et al., 2013)
- So might be very useful to further improve communication skills
- Consider the illness narratives approach?
- Target FN use within stakeholders’ roles
How can the FN and NEP help?

- *If I wasn’t claiming any money from anybody, nobody would care. They wouldn’t talk about the benefits of working and benefits to society they wouldn’t give a stuff about these things. What it boils down to is money. The rest of it is just kind of fancy rhetoric.* (Patient 1)

- Frame policies even more strongly as a means of genuinely improving lives, not as cost-cutting measure.
How can the FN and NEP help?

- My employers will see what I can do more clearly ... I’m hopeful this might help me get more targeted support ... I need some steps [to reach shelves] then I can do more, so maybe my GP can say that, or maybe my boss can change my duties a little bit. (Patient 28)

- Primacy of medical knowledge: FN makes employer “sit up and take notice” (Patient 19)
Summary so far

- Issues with naïve rationalism?
- Moral, socio-cultural and practical factors invoked by GPs and patients to contest decisions
- Both groups support the fit note
- Neither group wholly convinced it can overcome psycho-social issues (relationships, habitus)
- Employer “in room” with GPs and patients
- Next – ethnographic tracking of GPs, patients and employers in same sample
What about the workplace?

Previous work showed employers’ input influences doctor-patient interaction (Wainwright et al., 2011)

“It might send a message to employers concerning their duty of care to their employees”

Interesting how many GPs saw FN as a tool to shift employers’ practice as well as or instead of their own

So now (Wainwright et al., 2013)

1. Investigate employers’ and employees’ experiences of managing RTW post sick leave for chronic pain
2. Assess perceptions of the fit note in this context
Methods

- Qualitative study; suitable as enables in-depth exploration of macro/micro entities
- Semi-structured interviews (Denzin and Lincoln, 1994)
- \( n = 26 \) (13 employers; 13 employees) until saturation (Glaser and Strauss, 1967: Guest et al., 2006)
- Constructivist grounded theory (Charmaz, 2006)
- Ethical approval: REACH
### Participants’ characteristics

<table>
<thead>
<tr>
<th></th>
<th>Employees</th>
<th>Employers</th>
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<tr>
<td><strong>Gender</strong></td>
<td><strong>F = 5; M = 8</strong></td>
<td><strong>F = 4; M = 9</strong></td>
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<td><strong>3 yes; 10 no</strong></td>
<td><strong>3 yes; 10 no</strong></td>
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<td><strong>Universities (2)</strong></td>
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<td><strong>Academic (1)</strong></td>
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<td><strong>Software developer and engineer (1)</strong></td>
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Participants’ characteristics

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<thead>
<tr>
<th>Years worked for organisation (employees) or years in role (employers)</th>
<th>Mean (normally distributed data): 13.9</th>
<th>Range: 3 - 31</th>
<th>Mean (normally distributed data): 7.7</th>
<th>Range: 2 - 15</th>
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<tbody>
<tr>
<td>No. in team (employees) or no. people managed (employers; either as direct line manager or senior manager responsible for a large section of the company)</td>
<td>Median (not normally distributed data): 6</td>
<td>Range: 2 – 48</td>
<td>Median (not normally distributed data): 9</td>
<td>Range: 4 – 2,587</td>
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<td>Works full-time (FT), part-time (PT), on sick leave (SL) (employees only)</td>
<td>FT:9; PT:2; SL:2</td>
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<td>Years with pain (employees only)</td>
<td>Median: 4 (range 0.75 – 15)</td>
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<td>Chronic pain condition (employees only: some participants had multiple morbidities)</td>
<td>Fibromyalgia (5)</td>
<td>Back (4)</td>
<td>Joint hyper mobility syndrome (2)</td>
<td>Osteo-arthritis (2)</td>
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<td>Neck (2)</td>
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<td>Spine (1)</td>
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<td>Undiagnosed general (1)</td>
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Results 1: Need to make assumptions explicit as part of RTW process

• ‘I’ve had long conversations with [X] saying “d’you want me to ask if you are in pain or d’you want me to ignore it?” You know, we come in and say, “hi, how are you today?” and if [X] isn’t feeling well, I understand that, so I say “would you prefer me not to say that?” and [X] says “no, it’s fine, it’s okay to talk about it”, so we try and normalise it as much as possible’ Employer 9.
Results 2: Holistic knowledge used to assess authenticity of illness claims

• ‘It’s partly adjusting his hours but also making sure that if he felt he couldn’t do two hours, if after one hour 40 minutes he said “that’s enough” then he could go home. I know he’ll do his best, he always does. For that particular problem of pain I think that helps, but I think the most important thing is that he knew that he could say, and we’d believe him’ Employer 10
Results 3: Employees mirror employers’ need for trust: symbolism of physical aids

- ‘I’ve got a different chair…and I don’t have to twist and turn at all…they [the company] just agreed without question, which really helped me feel valued, and that’s really made a huge difference’ Employee 1
Results 4: Flexible use of guidelines to improve role disruption

- He wasn’t too comfortable with doing that, because, in his eyes I’m signed off sick, and so I shouldn’t be doing anything work-related, which I understand, but from my point of view, that helps me dread less the return to work. I knew that these things were being taken care of in my absence’ Employee 9

- Similar to GPs’ and patients’ appreciation of the fit note’s ability to harness grey areas (Wainwright et al., 2011)
Results 5: The fit note: positive, interrogative and authoritative

- ‘I believe the well note [sic] is better because it opens things up and is more transparent for us’ Employer 1

- ‘I think psychologically it makes a difference, because you feel like you’re getting somewhere. I mean, with the old sick note, wasn’t it just you’re sick and can’t go to work, or not sick and can go to work? That’s pretty categorical, and doesn’t appreciate the grey areas. I don’t think it’s as simple as that. And I think for me, it was nice to see on the back of that note, “fit for work” because it felt like a little bit of a victory, because I’d been unfit for such a long time and that kind of spurred me on to get back to work’ Employee 9
‘My own idea about sick notes is that they’re not really interrogative - they just sort of say, ok sign, here you go…that doesn’t really actually work when you’ve got to take that to your employer. This note [fit note] reflects that you’ve had a conversation with your GP, and your GP’s agreed these things with you…I know I felt more comfortable knowing that there’d been these conversations going to my employers, because I felt I had more to tell them, more than just, oh, I’m off sick… I’m sick because the doctor says I’m sick’ Employee 9
Conclusions

- Employers and employees mirror each other re: trust and re: flexibility being as important as physical adjustments – mutual value even for fluctuating CP
- Mirroring helps balance competing narratives of medical habitus (employee’s health) with business bottom line
- with MUS (Arrelov et al., 2007; Salmon et al., 2007)
- Consistent with previous research showing shared decision-making is important in RTW (Cohen et al., 2012)
Conclusions

- Employees’ track records particularly important for contestable conditions
- Limitations of study (sample size, generalisability) but thick description of data collection and analysis allows you to decide if findings applicable (Patton, 2002)
Where next?

- Be **open about often tacit phenomena** to enhance stakeholder communication (Black, 2008: DWP, 2013)

- **Use guidelines flexibly:** there is fear about this (HSE, 2009) and it is hard for chronicity (Munir et al., 2008); policymakers could further highlight best practice on this (HSE, 2013)

- **Highlight** the multiple benefits of the fit note in promoting behaviour change (**positive language and biomedical authority**): multi-faceted approaches are needed to change back pain beliefs and behaviours (Gross et al., 2012)
Where next?

• Research populations at work where trust and/or pre-existing knowledge of stakeholders does not pre-exist?
• Ethnographic tracking of same stakeholders
• Policymakers increasingly recognise the role of tacit knowledge
• Can we further improve sick listing by developing these skills even more?
• Change the nature of sick-listing? BJGP, OM etc. considering
Where next?

- Pain and resilience in the workplace? Very little known
- Resilience factors independently predict social interaction (Smith and Zautra, 2008)
- People high in resilience are more protected from the negative consequences of having CP (Zautra et al., 2005)
- Suggested pathways to resilience in people with CP
  - (Sturgeon et al 2010)
References

References

References

- Shiels, C., Gabbay, M., & Hillage, J. (2014). Factors associated with prevalence and types of 'may be fit' advice on fit notes: a cross-sectional primary care analysis. *British Journal of General Practice, 64*(620), e137-e143.