

Improving care pathways for people with Persistent Physical Symptoms

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Reader in Health Psychology

A quick word on terminology...

- Medically Unexplained Symptoms (MUS)
- Functional (Somatic) Symptoms
- Persistent Physical Symptoms (PPS)
- A patients' perspective:
like 'physical' more than 'unexplained'
 - ...and is 'unexplained' really accurate or useful?

Background

- 20% of the population have at least one PPS with associated disability
- PPS account for at least 15% of GP consultations and 30-50% of referrals to specialists
- Annual cost of PPS in England almost £18 billion
 - £3.1 billion direct cost to the NHS with a further £5.2 billion in lost productivity and £9.3 billion reduced quality of life. This compares to similar estimates of £17 billion for dementia, £7.5 billion for depression and £9 billion for anxiety.
- Our work is focusing on three PPS: Chronic Fatigue Syndrome (CFS), Irritable Bowel Syndrome (IBS) and Fibromyalgia.
- Both patients and physicians report dissatisfaction with consultations: care can be suboptimal
- Pathways are ill-defined and complex
- Aims of our work to map the individual and institutional factors that shape the PPS care pathway.

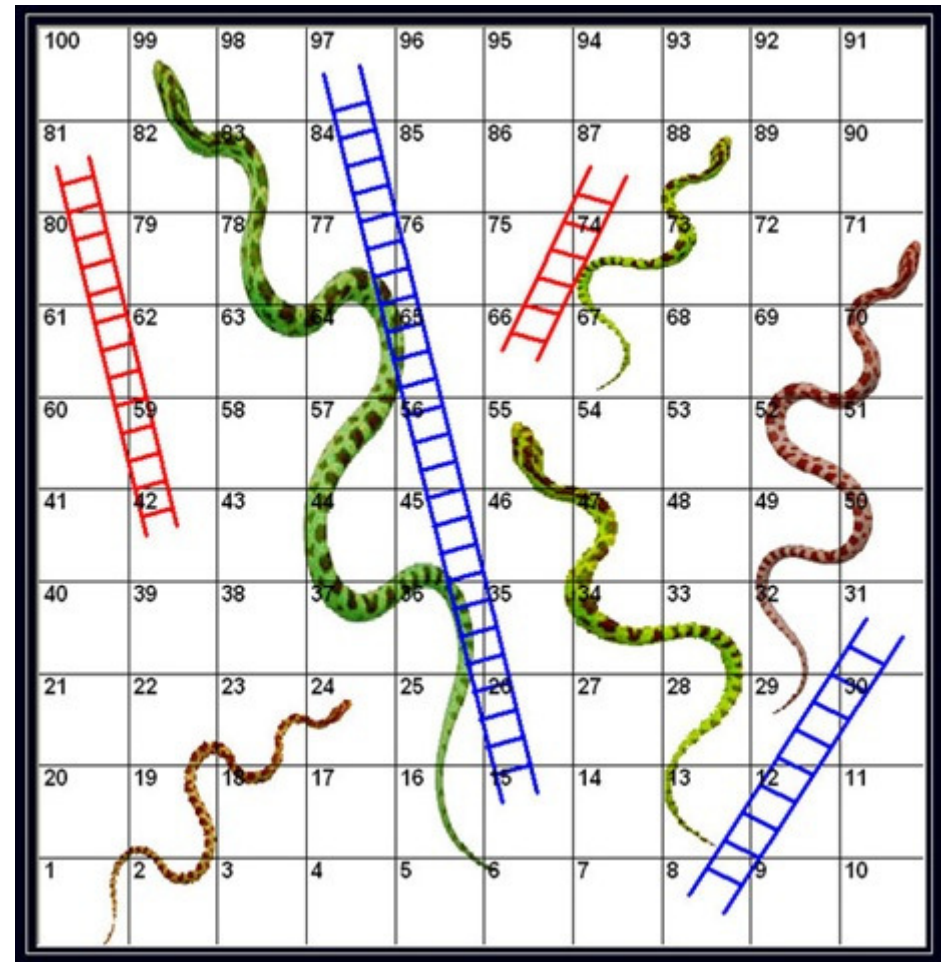
Research Process

- Patient interviews
- GP interviews
- PPS Expert Interviews
- Expert Panel
- Thematic analysis, testing and sharing findings



Headline Finding

- Its aleatory
- Who you meet, when, and what they believe, say and do.
- No one pathway
- Key factors that determine the direction the pathway can take



Individual Factors

- 1. The fear of 'missing something serious' and the diagnosis of PPS by exclusion
 - *I can remember [a patient] presenting with a number of things and then [he] started presenting with what I was quite sure were non-epileptic seizures but I really had to work fast because, you know, you see it coming. He's been to casualty and I thought 'right, if I don't get on top of this right away, he's gonna get into that system, he's gonna be in there. They'll do an EEG, it'll be mildly abnormal, if we're not careful he'll be in the First Fit clinic, and then he's gonna lose his license while he's waiting for the First Fit clinic and then we're off down the road'. I can remember almost literally going to casualty and saying 'you must not do this with this guy. This is really, really important'. You could see a whole trajectory ahead of you. (GP)*

The Merry Go Round

- *I got sent to neurology and he sent me back to orthopaedics and orthopaedics were the ones that referred me to neurology in the first place because they said it wasn't an orthopaedic problem. And then I went for a second opinion and she didn't get my files so she couldn't help me. And then even the mental health therapies, all these treatments, everything, they can't give you a treatment without knowing what they're treating you for. So I went through 15 years of that: 'just keep taking the painkillers, I'm sorry, there's nothing that we can do'. (Female, with CFS/ME and hypermobility syndrome)*

Symptoms over time

- Reduced tolerance to activity
- Limited repertoire of activities
- Decrease in general fitness
- Loss of muscle strength
- Sleep disruption and sequelae
- Alterations in mood
- Increase in symptoms
- Existential narrowing

Individual Factors

- 2. Morals, perceptions and a pyramid of empathy
 - Now if [someone] had lung cancer they would have everything thrown at them. But because they've got [MUS] it doesn't engender the same response from clinicians that a cancer diagnosis does. Even if you've got melanoma that's well-controlled, people tend to be more sympathetic with you than if you've got COPD [...] And then fibromyalgia and medically-unexplained symptoms is probably even lower [...] So there's definitely a pyramid that affects how...not 'nice' we are but I think it does affect clinician behaviour. [GP]

Who is the PPS patient?

Before falling ill, the vast majority of participants in our research had enjoyable, full, often stressful, jobs and careers, juggling multiple interests and commitments. Many vividly describe their 'crash' out of the work:

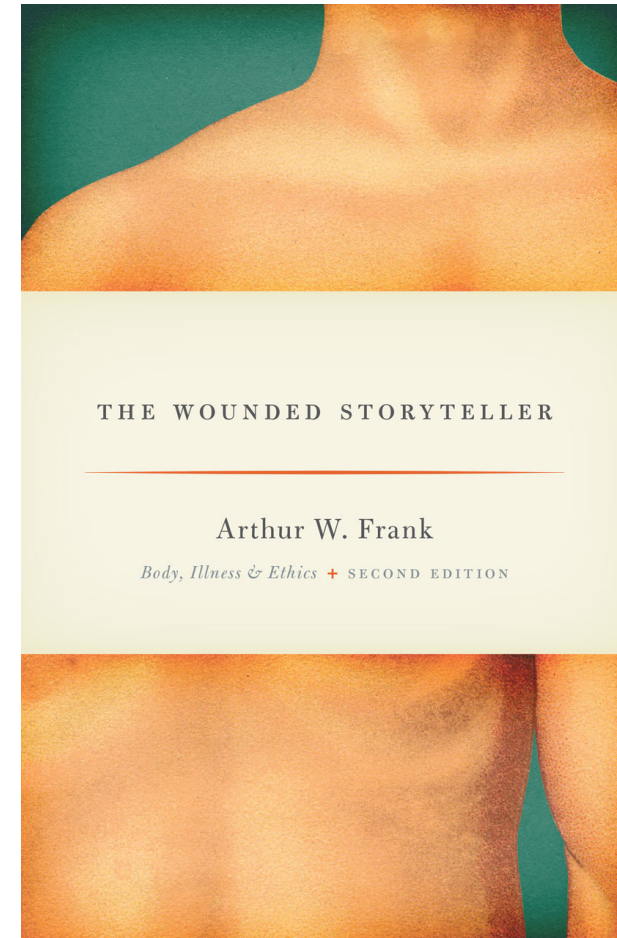
- “I used to work 50 hours a week, then 25, then 10 then I gave up”.
- “I’d been a hard worker and I was having problems and - for a GP to turn around and say to somebody who could work so hard, that there’s nothing wrong with you? It just blew a fuse in my head”

Individual Factors

- 3. Effective communication skills
 - Helping people make sense of symptoms
- What doesn't work
 - Re-attribution
 - Psychological stories about physical symptoms
 - *It's a physical illness that has mental problems. And I think that is so much core to the initial problem. As soon as anybody intimates that you've got a mental illness and that this is all just in your head, it just blows a fuse in your head because you keep thinking 'why do they think I'm making this up' (Person with PPS)*

Making Sense of Illness

- the *restitution* narrative
 - There and back again
 - Homeostasis
- the *quest* narrative
 - No way home, new normal
 - Allostasis
- the *chaos* narrative
 - Destructured
 - Failed Allostasis



Explaining Symptoms:

- An explanatory framework for Functional Somatic Symptoms in medical consultations.
- Chris Burton, LaKrista Morton,
- Alison Elliott, Jen Cleland
- Ruth Thomas, Vincent Deary



Headline Findings

- Stories that endorse reality of symptoms
- A biopsychosocial framework for explanation
 - Pain, alarm and cats.
- One that leads to action/management
- Longer consultations



I don't think the GPs always have the time to really go into it all, I think that's part of the problem [approving noises] in, really, such a small slot of time as well. And GPs are used to making a judgement on you and ME isn't like that is it? (Person with PPS)

We need to talk about symptoms

- One of the key themes emerging from our research was the challenge/difficulty/complexity/ of talking about PPS symptoms.
- At key points along a patient's pathway the quality of this dialogue can shape treatment trajectory and ultimately patient outcomes.

Self efficacy challenge for clinicians

“You feel that helplessness, not in your own skill, but in your own ability to change something that has lots of facets to it, including a subconscious facet” (GP)

When communication is critical

- Introducing PPS
- Discussing specific symptoms
- Framing tests
- Broaching the topic that psychosocial factors may impact on symptoms
- Moving on, what and where next?



Organisational Factors

- 1. Silo working and a lack of shared care planning
 - *At the moment, you're passed from pillar to post. Nobody wants to own it. Somebody's got to say 'the buck stops here and whatever else you've got, it's going to come through me. If I'm sending you to say, a rheumatologist, the results come back to me'. Somebody who owns the problem.*
(Person with PPS)

Organisational Factors

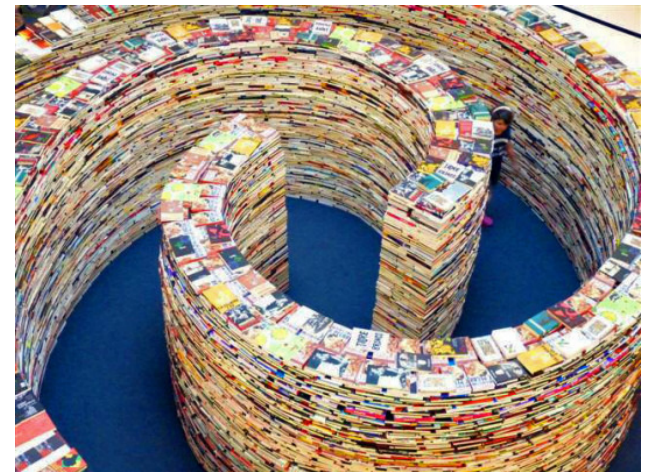
- *We need to get better at working across disciplines working transdiagnostically and across mind-body. This is such an important conversation for the health service as a whole. (GP)*
- *Functional problems manifest in neurology, rheumatology, cardiology, gastroenterology etc. It's easier to make progress when you recognise the impact of your diagnosis and treatment on other areas as well. We need to have knowledge and understanding of other associated conditions. We are good at diagnosis within our specialism, but poor at designing treatment packages that cut across specialties. (Secondary care professional).*

Organisational Factors

- 2. Benefits and Welfare System
 - *We've all seen it. Patients' symptomatology increases when they are coming up to a benefits review. Whether this is unconscious or conscious it happens. (Secondary Care Professional).*
 - *The system unwittingly traps patients in a cycle of benefits and illness. [...] Yet, DWP have no idea of the concept or the scale and cost of the problem. (Secondary Care Professional).*

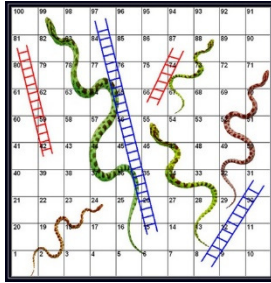
(Lack of) organisational factors

- No clear or single pathway
- Little support at Institutional/System level
- No GPs with special interest
- Reliant on local clinicians who (happen to) have an interest in these symptoms
- Education...

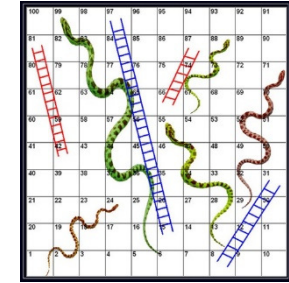


Education...

- *I spent some time in medical school in the chronic fatigue clinic so I sort of got a bit more coverage. But I think if I hadn't gone to that specific clinic, probably [I wouldn't know] very much at all. I don't remember being taught anything about it. (Registrar)*
- *It depends on who teaches you, because there's still a whole lot of people who don't believe in ME (GP)*
- *My GP's frustrated because he says 'I don't know where to send you. You've got so many little bits of problems. I've got nowhere I can send you to' He hasn't got the support network where to send a problem patient like me. (Patient)*



Summary: Luck



- *“I blacked out in A&E, [got] admitted and they ran tests and everything and they referred me back to the rheumatology department and I saw somebody who was from New Zealand I think, who was a registrar at the clinic. And she said ‘when was the last time you attended a pain management programme?’ and I said ‘what’s one of those, I’ve never been on one’ and she just looked at me and said ‘all this time and you’ve never been referred?’ and I said ‘no’. She said ‘would you like to go to one?’ I said ‘I would love to go to one, anything that would help’. And so I got referred on and that was how I met [expert local clinician] and the team there and got enrolled onto the pain management programme. And it was fantastic [...] And I thought ‘why couldn’t something like that have been offered following the initial diagnosis?’ because then all the years since then I would have been better able to manage it. And maybe would have been able to hold onto my job and various other things” (patient)*

What works in Primary Care

- Communication
- A Practice-wide approach, working with an identified cohort, awareness of distribution across GPs in the practice and role allied health professionals can play
- Consistency of care – seeing one doctor, with scheduled appointments, longer appointments
- Hold PPS as a working hypothesis rather than fixed diagnosis, making a positive diagnosis and focusing on symptom management
- Awareness of referral and support options
- Awareness of impact of tests
- Support and training for staff

Referral routes and services

- Identify local expertise
- Talking Therapies
- Health Trainers/Social Prescribing*
- Physiotherapy and exercise
- Pain management
- Medication review
- Fatigue clinic
- Sleep management
- Support groups & patient champions

* Consider severity and illness course

What works in secondary care?

- Multi-disciplinary teams & transdiagnostic working
- The “Durham Wrap”
- The CRESTA (Clinics for Research & Service in Themed Assessments) Fatigue Clinic
- Wider use of biopsychosocial approach across disciplines such as rheumatology, neurology, cardiology
- Strong links back to GP and Primary Care
- Support and training for staff

Thoughts for commissioners

- 20% of the population has a PPS associated with a disability, and cost estimates are £3bn, yet there is no mention of CFS/ME, FM, IBS, MUS or PPS in local Joint Strategic Needs Assessment
- Current provision is dominated by access and exclusion criteria. Our research found examples of where a Fibromyalgia diagnosis can prevent access to pain clinics, IAPT and CFS/ME service
- Commissioning for symptoms or syndromes?
- Education/HENE

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