# HAVE I MISSED SOMETHING?

Supporting patients presenting with Persistent Physical Symptoms



Welcome to the WiseGP newsletter, highlighting how research can help Wise General Practices address the top challenges facing primary care...

### **Editorial by Professor Carolyn Chew-Graham**

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Persistent Physical Symptoms- relationships and continuity underpinned by explanation

### **Evolving language**

Persistent physical symptoms (PPS) are symptoms that are there some or all the time, and which can be difficult and challenging to live with. Sometimes patients have an underlying health condition that triggers the symptoms, whilst some people have the symptoms by themselves, in what are commonly known as 'functional disorders'.



Inclusion of PPS within NHS resources is a far cry from 50 years ago, when a label of 'hysteria' was applied, <sup>1</sup> with the term 'heartsink' being devised in 1988 to describe people consulting frequently with PPS. <sup>2</sup> Move forward to the 21<sup>st</sup> century and changes in understanding have led to an evolution in terminology, from 'Medically Unexplained Symptoms' to PPS, a term that is preferred by patients.

#### Response to people with PPS

People with PPS have been reported to feel dissatisfied with consultations and that their symptoms are dismissed, particularly when investigations are normal. <sup>3</sup> Research suggests that GP continue to find it difficult to manage people with PPS. <sup>4,5</sup> A qualitative study conducted early in my academic career illustrated the perspectives of a sample of GPs on their work with people with unexplained symptoms. <sup>6</sup> One GP reported the impact on him:

"Some make your stomach churn when they come in . . . very nervous. They make it very clear they are taking charge; and they do, they take charge, and there's nothing you can do." (GP 5)

Evidence suggests that medical school training doesn't fully prepare doctors to work with people living with PPS. <sup>7</sup> A study exploring perspectives of medical students on Fibromyalgia (FMS) illustrated negative attitudes influenced by the 'hidden curriculum', their clinical teachers, and a lack of formal curriculum teaching around FMS, which led students to perceive it as low priority. Encountering a person with FMS increased knowledge and altered perceptions of the condition. Teaching about FMS and PPS, needs to be consistent to improve the knowledge and attitudes of future clinicians.



#### **Acknowledging symptoms**

The key role of the GP is to listen to the patient share their problem and acknowledge their symptoms: the patient needs to know that the GP believes them. This is the start of beginning to support and manage people with PPS. GPs can refer people living with PSS to NHS talking therapies<sup>8</sup>, but it is vital to emphasize to the patient that their symptoms are not 'all in their mind'. GPs can also refer people to resources such as the 'Recovery College'<sup>9</sup>, which again can help reassure the patient that their symptoms are believed, have an explanation and that they are not being dismissed. Looking to the future, a feasibility study has suggested that brief training for GPs to work with people with PPS could be acceptable, low cost and low risk, though a fully powered trial is needed. <sup>10</sup>

#### Working towards an explanation

In the study that explored GPs perspectives of working with people with unexplained symptoms,<sup>6</sup> participants emphasised the importance of establishing a good doctor–patient relationship as the basis of successful management. GPs described the need to listen, show empathy and take an interest in order to gain trust. The value of continuity was emphasised, which can help to build a story or explanation of someone's symptoms, by exploring the wider context of their presentation:

"One of the advantages you have in general practice is, I suppose, to build up parts of a story over a period of time, rather than doing it all in one day or one consultation . . . I think you have to try and not leap to a diagnosis." (GP 8)

Practices are struggling to balance the need offer continuity with the national requirement to prioritise access.

## The future – will a new term be more acceptable to people living with PPS?

ICD 11 now suggest that we use the term 'Bodily Distress Disorder' - characterised by the presence of bodily symptoms that are distressing to the individual and excessive attention directed toward the symptoms, which may be manifest by repeated contact with health care providers. We do not yet know whether this new term is acceptable for people living with PSS – have you ever discussed with your patients or Patient Participation Group what terminology they consider to be acceptable?



PPS are common, accounting for up to 45% of all general practice consultations<sup>11</sup> and are associated with significant functional impairment, psychological distress and costs- to affected patients, healthcare professionals and the wider health service and economy.<sup>12-14</sup> These significant costs can often stem from over-investigation.

Patients with PPS may present in distress due to a lack of answers, whilst doctors can feel powerless in the face of diagnostic uncertainty. Fear of missing serious pathology and possible litigation can spark unnecessary tests, over-treatment and referrals to secondary care, which can ultimately heighten anxiety and potential harm to patients.<sup>6</sup> A focus on physical symptoms can mean that opportunities to discuss emotional wellbeing and provide support in coping with PPS can often be overlooked by doctors.<sup>15</sup>



## The WiseGP Approach- Shifting the focus

GPs have a role in helping people with PPS to make sense of their symptoms- shifting the focus from diagnosis to explanation.<sup>15</sup> Central to this process is knowledge work,<sup>16</sup> which begins by exploring a problem and responding to cues to possible distress, whilst trying to understand the impact of symptoms. Evidence suggests that experience of adverse childhood experiences, poorer physical functioning and a perception of poor financial wellbeing can all increase the likelihood of PPS, hence why understanding the wider context is so vital.<sup>17</sup>

## Harnessing creative capacity...

In the WISDOM course,<sup>18</sup> the importance of harnessing a patients' creative capacity is discussed, so they can be involved in co-developing an explanation for their symptoms.<sup>16,19</sup> Patients have a lifetime of experience managing their 'work of daily living'- the ups and downs of everyday life. Everyone has resources that they draw on to manage everyday tasks- the resources of their creative self. The diagram below illustrates this concept and how exploring the wider context of a patients' presenting symptoms can help harness their creative capacity to co-develop an explanation and management plan.

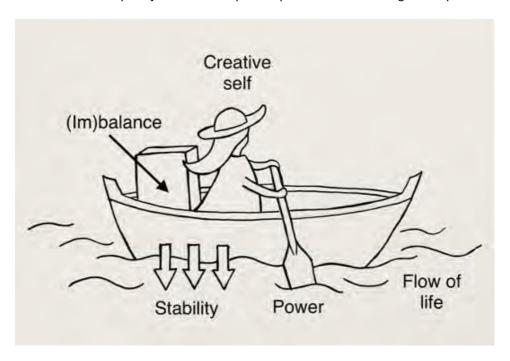


Figure 1: Imagining out creative self (adapted from Reeve in Dowrick)19.

Let's imagine a patient with PPS sat in the boat. Their illness could have disrupted their flow of daily life and created extra work for them to do. As clinicians, we have a role in helping our patient recognise the extra work they are doing to power themselves and the impact this could be having on their health. We can help to restore their balance and stability, by exploring and understanding the daily work our patient does, the context in which they do it and the internal and external resources that help them. We need to understand what provides them stability and aids their flow through daily life, then we can explore solutions together.

It's easy to see how the boat could capsize within turbulent flow if it's carrying too much weight and unbalanced- is this diagram something you could use when trying to involve patients in co-developing explanations for their symptoms and management plans?

When developing explanations, use of metaphors can help build understanding.<sup>20, 21</sup> By drawing on the model of creative capacity, individualised management plans can focus on harnessing a patients' strengths- aspects of their life that help them gain stability.<sup>19</sup>

## Managing uncertainty

Being realistic with patients about the likelihood of investigations finding any pathology can help to avoid disappointment at 'nothing being found'. GPs can also help to avoid harm through over-investigation and treatment by managing their own anxiety when dealing with uncertainty. It can be helpful to share uncertainty with patients and colleagues, to facilitate informed shared decisions about further investigation and management.

Continuity of care is pivotal as the process of developing a shared explanation and management plan can take time, whilst evaluation of the outcome is the third key aspect of knowledge work. This enables explanations and plans to be reviewed and refined over time, supported by safety netting. By addressing PPS satisfactorily, we may help to prevent patients from developing further persistent symptoms or becoming frequent attenders.

## Multidisciplinary approach

A co-ordinated multidisciplinary approach is central to supporting people with PPS, which brings together clinicians from a range of specialties (including general practice, medicine, nursing, psychiatry, occupational therapy, and physiotherapy) and integrates physical and mental healthcare services. <sup>22</sup>



## The WiseGeneralPractice Approach

The ability of GPs to manage complexity when supporting people with PPS demonstrates their distinct expertise in generalism. How can we use these skills to help our wider general practice team and patients?

holistic support <sup>24</sup>. Read more here.

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## The WiseGeneralPractice Approach

- A WiseGP GEM highlights how sharing our approach to these complex cases with medical students can give them a greater understanding of the challenging work we do and encourage them into general practice careers. <sup>23</sup> Perhaps something to consider next time you have a medical student sat in on your clinic?
- Perhaps you could also take inspiration from a QI project summarised in a GEM, in which a team of GPs actively identified people with complex lives who would benefit from
- Evidence suggests that junior doctors can feel anxious when consulting patients with PPS, with some over-investigating or reporting a self-perceived lack of competency. Signposting your GP Registrars to the WISDOM course could help them to feel more confident when consulting these patients by developing their knowledge work skills to develop shared explanations and management plans.

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