



## Contested pain: Managing the invisible symptom

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Received Date: July 25, 2018; Accepted Date: August 21, 2018; Published Date: January 08, 2019

### Abstract

Drawing parallels between chronic pain in Vulvodynia and acute pain in Sickle Cell Disease, our opinion is one that challenges the prevailing medical model by contrasting the experiences of pain sufferers and reflecting on the lenses through which the pain is seen. In both chronic illnesses, the patient has self-knowledge that the healthcare professional does not always recognise. Lack of access to adequate pain relief in times of crisis; lack of continuity of care; and pain flare-ups means that patients often find themselves needing to prove the existence of their pain to a healthcare professional every time they need prescription relief. Patients voice concerns and struggle to manage the tension between needing to control pain and needing to control medication intake. To make best use of their interactions with healthcare professionals, patients informally monitor their bodily experience and bring symptoms to the attention of healthcare professionals, of which is usually met with a biomedical discourse that isolates the patient from what should be a collaborative relationship. Ultimately, this commentary deliberates on the opinion that both patients and doctors should be working together on a more effective approach to pain management.

**Keywords:** Chronic Pain; Pain Management; Medical Model; Doctor-Patient Communication

### Commentary

Pain syndromes are well known as difficult to diagnose and treat [1], yet chronic pain is prevalent in 35% to 51.3% of the population [2]. While the burden of chronic pain increases with age, prevalence of chronic pain of up to 30% in younger people has been estimated [2] and services have been reported to be inadequate [3]. By drawing parallels between the experiences of patients with two quite different pain conditions, we aim to entice readers to join us in rebooting a much needed discussion on the practical application of the biopsychosocial approach to pain management.

Sickle Cell Disease (SCD) and Vulvodynia are distinct pain conditions with the shared commonality that they illustrate how pain is often still poorly managed. In both cases, the patient has self-knowledge that the healthcare professional does not always recognise; despite self-management of symptoms being considered the optimum goal. Lack of access to adequate pain relief in times of crisis; lack of continuity of care; and pain flare-ups means that patients often find

themselves needing to prove the existence of their pain to a new healthcare professional every time they need prescription pain relief. In order to make best use of their interactions with healthcare professionals, patients informally monitor their bodily experience and bring symptoms to the attention of healthcare professionals, which is usually met with a biomedical discourse and too often isolates the patient from what should be a collaborative relationship [4]. Indeed, medical literature on pain tends to focus on its identification and management with drugs or physiotherapy rather than the patient experience of living with the condition, reinforcing the biomedical view of the patient in the literature as well as the consulting room [4]. Resources that do mention psychological effects of suffering pain tend to be biomedical in their focus, failing to address the divergence of experience of a particular population [3]. If we concede that the shared talk of healthcare professionals is reflected in the journals they read and publish in, then the discourses therein serve to perpetuate this biomedical status quo.

Pain is the most common symptom of SCD and sometimes has no precipitating events making the condition tricky for both patients and doctors to manage. SCD is a group of inherited red blood cell disorders that causes many symptoms including anaemia, pain and damage to vital organs. SCD affects haemoglobin (a protein that carries oxygen inside the cell) and is the most common genetic disease in the US. In the case of SCD, interpersonal rather than pharmacological factors are associated with better pain management in hospital [5]. Successful adjustment to SCD involves cognitive restructuring: changing one's beliefs and goals, acceptance of responsibility for symptom management and information seeking [6], strategies which are not dissimilar to those recommended for pain related to other medical conditions. Severe crises often require hospitalisation and narcotic pain relief that could be sub-optimal due to staff fears of addiction [7]. When attending hospital, SCD patients report poor pain management, stigmatization and excessive staff control [7].

It would appear then that this problem must compound itself. Doctors fear patients seeking pain relief which can be addictive, the patients feel that their experience of symptoms is challenged and treated with suspicion, and psychosomatic explanations for symptoms are legitimised in discourse among doctors. As one vulval pain patient so succinctly puts it: "You know that if you go into a doctor's surgery and say, 'oh I suffer from this' and they look at you really strangely, in one ear, out the other, they don't wanna know..." [8] Patients adopt strategies to avoid hospital admissions because of the way they are treated by staff; as evidenced through the voice of patients "They don't believe you, they're biased against sickle cell people, ...They treat us like liars when we are in pain, and sometimes if they don't understand what triggers the pain then they think that you're lying" [7].

Patients with Vulvodynia have voiced their frustration with the lack of understanding from healthcare professionals; the lack of transparency in the staff-patient relationship; and feeling misunderstood. For example, in our research with women suffering chronic vulval pain and in relation to the ways in which this manifests in terms of treatment options: "What are they actually thinking of me, I mean, if my best treatment is going to be 'to get into a relationship' what do they actually think?" [8].

Vulvodynia is a chronic pain condition, which is defined by the International Society for the Study of Vulval Disease (ISVVD) as 'vulvar discomfort, most often described as burning pain, occurring in

the absence of relevant visible findings or a specific, clinically identifiable, neuralgic disorder' [9]. Vulvodynia is relatively common with a study in the US putting the prevalence as high as 16% of the general population [10]. Unfortunately, little comparable data exists for other countries, however a prevalence of 2.8–9.3% in a UK county has been suggested in one study [3]. Women who seek help for this condition typically visit several physicians before being given a diagnosis and many abandon their search for help when their reported symptoms are dismissed as being all in their heads. Indeed, little understanding of vulvodynia has been found among junior gynaecologists [11], which tallies with patient's own experiences and the limited number of teaching hours devoted to this topic. For example, a study of teaching related to pain in medical schools across Europe found that the number of teaching hours devoted to this topic were well below what they should be given the degree to which pain is a public health problem [12]. Online training modules have recently appeared [12], which suggests some recognition of the problem and an attempt to disseminate knowledge of the condition. Given the importance attached by physicians to clinical findings, it is not surprising that patients also seek to have the existence of their pain objectively proven. Studies that seek to engage with how pain sufferers perceive themselves have identified a complex relationship between patients' own perceptions of their symptoms and their medical diagnosis [13]. Increasingly, sophisticated diagnostic tests do not provide the answer to the pain conundrum as we can see from interviews with doctors about seeking causes for pain [14]. It is evident that the frustration is felt on both sides of the staff-patient relationship, trying to use existing methods of medicine to see an invisible symptom. In the absence of medical evidence, it is common for patients to be offered psychosomatic explanations for their symptoms, which they in turn reject [15].

So, should both patients and staff be working together on a more effective approach of sharing their knowledge? - Yes! Patients learn optimal pain coping strategies for themselves, which they can explain to doctors in order to foster a more collaborative and holistic biopsychosocial approach to healthcare. Both parties could step back and assess their assumptions. With qualitative health research we can start to build a better understanding of pain that is based on rich patient experiences, rather than relying on an outdated biomedical model. While it is clear that there is a strong movement to include patients and the public in service development, and evidence of patient involvement in pain management tools [16], services remain patchy [3] and we still have some way to go before this approach becomes mainstream for all practitioners. There are educational elements that need addressing for both patients and doctors around the mode of operation of analgesics and their appropriate use [17]. We have come part way with this by updating curriculums ensuring that medical students receive some level of formal training, as well as exposure to the stories of patients with chronic conditions. Fresh discussions on the need to apply a biopsychosocial approach to healthcare have begun in the field of wound management; to bring us that step closer to a solution, it is now time for us to revive this debate for the successful management of pain.

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