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# Blame, shame and hopelessness: medically unexplained symptoms and the 'heartsink' experience

## Background

'Heartsink' patients present a moral dilemma. We recognise their suffering, but at the same time struggle with the feelings they trigger in us. Patients also experience negative feelings. Without a diagnosis they lack a narrative or vocabulary to make sense of their own suffering.

## Objective

This article explores some of the challenges faced and strategies utilised when managing patients with medically unexplained symptoms.

## Discussion

Doctors and patients often experience frustration and helplessness in consultations around medically unexplained symptoms. Without a diagnosis, patients lack social legitimacy as 'sick' people with 'real' illnesses. They often describe feeling blamed for their own distress. Because of this, they can experience deep feelings of worthlessness and shame. Patients with a history of abuse can be particularly vulnerable. Management includes validating their suffering, helping them construct appropriate explanations for their distress and providing empathic interpersonal care, while minimising the risk of iatrogenic harm.

## Keywords

chronic disease/therapy; consultation, doctor-patient relations; communication, doctor-patient relations; psychiatry, general practice

discourse on life, impaired his ability to enjoy himself and destroyed my positive feelings?'<sup>1</sup>

'Heartsink' patients offer a moral dilemma. We recognise their suffering, but at the same time struggle with the feelings they engender in us. These patients can trigger aversion, fear and even hostility.<sup>2</sup> As doctors, we are not proud of these feelings. Most of us are motivated to practise medicine because we gain satisfaction from solving medical problems and helping patients and their families.<sup>3</sup> Feelings of helplessness and guilt are not part of our vision of a good doctor.

However, patients who make your heart sink commonly present in general practice and many have medically unexplained symptoms.<sup>3-10</sup> Like their doctors, these patients have to manage difficult feelings. Without a diagnosis, they often feel they have to fight for the right to access care and they lack a narrative or vocabulary to make sense of their own suffering.<sup>11</sup> Many describe feeling like medical orphans<sup>12</sup> without a legitimate place in their social or medical worlds.<sup>13</sup>

In this environment of shared blame, shame and hopelessness, it is still necessary to provide quality care. These consultations are often unsatisfying and difficult for doctors and patients.<sup>14-19</sup> In this review, the focus is on the experience of the doctor and patient, the challenges inherent in the therapeutic relationship, and the construction of meaning through explanations and narrative.

## The experience of the doctor and patient

### Understanding the doctor's experience

Most doctors recognise the importance of the therapeutic relationship and feel responsible for it

In 2004, Andre Matalon wrote a personal memoir describing a 20-year relationship with a patient who was demanding, difficult and profoundly unhappy. Through Matalon's account, we see a patient with multiple unexplained symptoms, whose life 'gradually contracted into doctor visits, medical treatments and hospitalisations'.<sup>1</sup> As his general practitioner (GP), Matalon struggled with feelings of worthlessness, frustration, anger and guilt. It is easy to identify with Matalon's difficulties in being a 'good' doctor when he wrote 'How could I be angry with a person who suffered disease and depression that prevented him from any rational

even when it is difficult.<sup>20</sup> However, they fluctuate in their willingness and capacity to engage with patients' emotional cues.<sup>21</sup> Many doctors feel overwhelmed by the task of caring for patients with medically unexplained symptoms,<sup>15,22–24</sup> and lack confidence in their ability to meet patients' needs.<sup>25–27</sup> Some distance themselves from their patients as a way of managing their own difficult feelings.<sup>28,29</sup> Other doctors burn out and become interpersonally ineffective.<sup>30</sup>

### Understanding the patient's experience

Patients with medically unexplained symptoms often complain that they are not taken seriously.<sup>17</sup> Their medical notes can follow them around like a criminal record: 'I compare it with being ... wrongly accused of a crime...I'm made to feel bad when I've actually done nothing wrong'.<sup>31</sup> Some patients quietly disengage from health services altogether when they 'cannot face

engaging in a process that invalidates their pain'.<sup>32</sup>

In Western culture, symptoms in the mind can be seen as moral weakness.<sup>13,21,31,33–35</sup> The actions of the mind are seen to be a choice and a responsibility rather than a symptom or an illness. Sufferers strive to become 'good' patients: strong, in spite of illness and disability and not 'crazy, lazy, illness-fixed or weak'.<sup>36</sup> They value doctors who take their concerns seriously and listen empathically.<sup>37</sup> *Table 1* outlines the evidence around successful strategies for the management of medically unexplained symptoms, including the importance of an empathic therapeutic relationship.

**Table 1. Managing the patient with medically unexplained symptoms**<sup>19,20,75–78</sup>

Managing the patient with medically unexplained symptoms should include:

- Validating the patient's experience by acknowledging that the symptoms are real and distressing. It is also important to validate the frustration and uncertainty experienced when there is no concrete diagnosis
- Making an empathic connection so the patient feels understood
- Establishing common ground by agreeing on the nature of the problem and the goals of treatment
- Offering a detailed biopsychosocial explanation of symptoms using language and imagery that the patient understands
- Naming the illness appropriately. This may involve diagnostic terms, or explanatory metaphors (eg 'stress headaches')
- Limiting iatrogenic harm: focus on care rather than cause or cure<sup>19</sup>
- Establishing clear boundaries around each consultation
- Addressing the body: examining appropriately and using physical therapies such as massage, hydrotherapy and exercise as appropriate
- If necessary, providing symptomatic relief
- Addressing your own needs: use opportunities to debrief and reflect on the therapeutic relationship (eg. using Balint groups or peer discussion)

### The consultation and dynamics of the therapeutic relationship

#### Changes in the contemporary therapeutic relationship

The doctor–patient relationship has undergone significant changes in recent decades. Patients are more informed and able to access and discuss extensive medical information online. The doctor has become more of an interpreter of knowledge, rather than the sole expert in the consultation.<sup>38</sup>

*Table 2* shows the way medically unexplained symptoms are detected and understood in the clinical encounter. Because some symptoms cannot be observed, but are inferred from conversation, there is potential for substantial disagreement between the doctor, the patient and other health professionals around the aetiology of the illness and the nature of the distress.

**Table 2. How do we understand medically unexplained symptoms?**

The experience of medically unexplained symptoms can be known through evidence that is explicit and evidence we need to infer through conversation and an understanding of the therapeutic relationship. Kirmayer calls this the epistemology of distress.<sup>29</sup> Evidence includes:

#### Explicit cues

- Verbal report of distress (symptoms)
- Local behaviour impaired (signs)
- Global behaviour impaired (disability)
- Physiological derangement (investigations)

#### Inferred information

- Psychosocial context
- Personality characteristics
- Private experience of distress
- Intrinsic motive for the sick role (primary gain)
- Extrinsic motive for the sick role (secondary gain)

Inferred information is only known through conversation. It is often understood differently by different health professionals, and interpretations may change over time. It is often the source of disagreement between patients, their carers or families, and health professionals.

### Contested illnesses and the problem of power in the consultation

Patients with medically unexplained symptoms are in a difficult social position. Without a diagnosis, they lack social legitimacy as sick people.<sup>39–41</sup> Many hunt online for a reason for their suffering<sup>42</sup> and present to their doctor seeking a particular diagnosis. These patients become invested in 'illnesses you have to fight to get':<sup>43</sup> so-called 'contested illnesses', such as multiple chemical sensitivity, chronic fatigue syndrome and fibromyalgia.<sup>39,43–45</sup>

These patients invest significant work, time and energy to earn their status as credible

patients,<sup>43,46–49</sup> fighting for 'permission to be ill'.<sup>13</sup> This is a delicate balance; they have to provide compelling evidence of their incapacity so they can legitimately seek support, while not being seen as passive and incompetent so they can retain their dignity and self-worth.<sup>11,22</sup> One author describes this as the balance between being seen as a helpless victim or a courageous coper.<sup>11</sup>

When patients become convinced they have a physical disease, and there are no physical signs, there is the potential for significant conflict in the consultation. The result is often 'a duet of escalating antagonism',<sup>30</sup> a consultation that various writers have described as a law court, a medieval siege or a tug of war.<sup>36,50</sup> This sort of contest is dangerous and the outcomes depend on who has the most successful tactics and strategies, rather than clinical need.<sup>21</sup> They can also be confusing. In the drive to appear physically distressed but emotionally stable, they can often convey mixed messages. Patients often use graphic and emotional language<sup>51</sup> but often appear distant and detached.<sup>52,53</sup> GPs can also respond in confusing ways; for instance, doctors commonly reassure patients and then make a referral 'just to be on the safe side'.<sup>54</sup> It can be easy for the consultation to deteriorate and become weighed down in hopelessness on both sides. Strategies for managing contested illness are detailed in *Table 3*.

## Issues around childhood trauma

There is a strong association between medically unexplained symptoms and childhood abuse.<sup>55–58</sup> Unfortunately, this makes the consultation dynamics difficult as there are parallels between the parent–child and doctor–patient relationship. Adult survivors of childhood trauma recall multiple attempts to tell a parent or doctor that something was wrong, which were met with denial and a lack of nurture. It is easy to see the parallel with medically unexplained symptoms: the consultation can repeat a pattern of hiding feelings, distrusting caregivers and seeking acknowledgement of suffering. Sensitive appreciation of the parent–abused child interpersonal dynamics can help avoid an unintentional repetition of this pattern.<sup>55</sup> Careful and deliberate validation of suffering is essential in establishing and maintaining trust in these situations (*Table 1*).

## The iatrogenic consultation

Traditionally, patients with medically unexplained symptoms have been thought to 'somatise': to express psychological distress in physical symptoms. However, recent evidence suggests that many patients ask for emotional support.<sup>17,51,54,59–62</sup> If doctors do not respond to these emotional cues, patients may feel that the doctor is only interested in somatic problems.<sup>16,62,63</sup> In this way, the consultation itself can be iatrogenic, by entrenching focus on physical problems.<sup>18,21,64,65</sup>

## Formulating an appropriate explanation

### Illness narratives

Medically unexplained symptoms present a profound crisis of meaning in Western culture. When the expected story of symptom, diagnosis, therapy and cure is not forthcoming, patients are left without narrative, lost in what Kirmayer describes as 'a semantic no man's land'.<sup>66</sup> Most doctors do allow patients to tell their story, but in an unstructured way.<sup>20</sup> The narratives of people with medically unexplained symptoms

are often chaotic and this is reflected in the chaotic structure of their consultations.<sup>67</sup> While most doctors try to reassure patients,<sup>68,69</sup> what is often missing is an explanation that links the patient's beliefs and concerns with a future direction for care.<sup>62,67</sup> Several studies have shown that simple explanations improve outcomes.<sup>70–72</sup> Frank believes that most illness stories carry a sense of being 'shipwrecked by the storm of disease'. Creating an explanatory framework that respects and incorporates the patient's models of illness and a future direction for care involves using storytelling 'as repair work on the wreck'.<sup>73</sup>

Psychiatric and psychological explanations are abstract and often described using metaphors. These explanations 'have a social life'<sup>24</sup> as 'metaphorically transmitted diseases'.<sup>74</sup> Explanatory frameworks change over time, adapting to the patient's understanding and experience, and in response to the patient's interactions in their communities. They help construct meaning out of distressing symptoms. Good explanations for medically unexplained symptoms are therefore individualised, subject only to the doctor's ingenuity in fashioning

**Table 3. Managing contested illnesses**

- Validate the subjective experience of illness (eg. 'I can see you are experiencing a lot of pain, and the constant fatigue must be getting you down')
- Use the patient's words and frameworks if you can. For instance, if a patient believes they have fibromyalgia, their symptoms are consistent, and they are feeling supported by the diagnosis, you may wish to use the term
- Use their language to broaden the agenda to include physical, psychological and social strategies for management (eg. 'patients with fibromyalgia seem to respond best to a combination of treatments. I'd like to look at strategies to address the pain, but also see if we can help you manage stress, because stress seems to make fibromyalgia pain worse')
- Involve a multidisciplinary team
- Keep a focus on active intervention (eg. 'I know you are often quite tired, but fibromyalgia patients do better if they undertake some regular light exercise. What exercise are you able to do at the moment?')
- Explain that different strategies work for different people, so you will have to try a number of strategies to see what works in their particular case
- Work out what you agree and disagree on. For instance, you may have to explain that some treatments your patient has sourced over the internet are unproven, expensive or risky
- Harm minimisation: maintaining a non-judgemental, open relationship will allow your patient to discuss alternative treatments that have the potential for harm.
- Keep an eye out for other diseases. Patients with medically unexplained symptoms often have co-morbid physical illnesses. A regular physical health assessment can help screen for unexpected co-morbidity

**Table 4. An example of an explanation for a patient with medically unexplained illness and a past history of trauma\***

Catherine, aged 42 years, has a debilitating and frustrating history of generalised joint pain and fatigue. Despite numerous investigations, referrals and interventions, she continues to have distressing symptoms that interfere with her ability to work and manage her family. During a health assessment, you ask Catherine what she thinks is causing her pain. She says, 'Well, the doctors say I'm depressed, but I'm not mad or anything. This pain is real: it's not like it's all in my head. I think I'm just worn down. I've had a tough life with too much to cope with'.

You ask her to tell you about her life and she tells you she's worked hard on the family farm since she was a child. As a teenager, she was the principal carer for her mother, who had crippling rheumatoid arthritis. She continued to be her mother's sole carer until her mother was placed in a nursing home when Catherine was in her early 30s. Catherine says, 'I never really had much of a life: I had my children late, and then my husband left, so I've just had to manage.' When you ask about any childhood trauma, she details longstanding physical abuse from her father and brother, which she has never disclosed.

You agree that she does not have depression and try to find an explanation that respects her traumatic history but allows room to recover. You explain that she has had a number of injuries to her self: she has been 'broken' by all the troubles she has faced. But you tell her it is possible to piece things together like a mosaic and create a new, strong self out of the pieces. You show her a picture of a mosaic vase that comes from something broken, but becomes something functional and beautiful. She finds this image helpful and you begin to talk about strategies for helping her piece her life together. For the first time, she thinks it may be helpful to try psychological as well as physical treatment.

\*This is a hypothetical case used in a mental health workshop in 2013. The explanation has been provided by Dr Tamara Ford, an Australian rural GP (personal communication 31 October 2013).

explanations within which both doctor and patient can work'.<sup>21</sup> An example of an explanatory framework is given in *Table 4*.

## Conclusion

Patients with medically unexplained symptoms are challenging to manage. Without a diagnosis, they struggle to be accepted as real patients with real illnesses and often describe feeling blamed for their own distress. Because of this, they can experience deep feelings of worthlessness and shame. This can lead to defensive behaviour in medical consultations, which can trigger anxious or even hostile feelings in their doctors. GPs can also feel a sense of hopelessness and frustration. Helping patients construct an acceptable illness narrative by providing appropriate explanations is a first step in engaging patients in care. Validating their suffering and providing empathic interpersonal care are key strategies for managing their distress and minimising iatrogenic harm.

## Author

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