Managing medically unexplained illness in general practice

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Background

Patients with medically unexplained symptoms commonly present to general practice and experience significant disability. Many have a history of trauma, which complicates the therapeutic relationship between doctor and patient. Because diagnosis is an expected outcome of a medical interaction, doctors and patients can feel frustrated and lost without one.

Objectives

This article provides practical management strategies that general practitioners (GPs) can use when patients present with medically unexplained symptoms.

Discussion

Three types of common presentations are discussed. Enigmatic illnesses occur when the doctor and patient believe that a biomedical disease is likely, but a diagnosis is not forthcoming. Contested illnesses occur when a patient is committed to a diagnosis the doctor does not accept. Chaotic illnesses occur when symptoms are over-determined; there are many possible diagnoses, but none fully explain the complex web of distress the patient experiences. Common strategies for managing medically unexplained symptoms are discussed, and specific approaches to each presentation are outlined.

Patients with medically unexplained symptoms commonly present to general practice,[1,2] and their symptoms can be severe and disabling.[3,4] The challenge for the general practitioner (GP) involves managing individual symptoms, but also crafting a framework for the chronic care of patients with significant ongoing illness.[5,6] For many patients, this includes management of comorbid depression and anxiety,[2,7,8] and ongoing psychosocial stress.[9]

This article provides an approach to the management of patients with medically unexplained symptoms. Three ways these patients may present are outlined, and some of the strategies that may be utilised to alleviate their suffering are discussed. The article does not address the care of patients who are malingering, patients with individual syndromes (eg irritable bowel syndrome) or patients with hypochondriasis.

Why is diagnosis so important? The importance of validation and explanation

Diagnosis is not just a tool to guide management. It is an expected part of a medical interaction. To be left without a diagnosis is to be left without a story, with no way to make sense of distressing symptoms,[10,11] or explain the disability to friends, family and workplace colleagues.[12,13] No diagnosis means no prognosis, so patients live with perpetual uncertainty.[14–16] Diagnosis also 'authorises' suffering, establishing illness as legitimate and socially acceptable.[17] It is difficult to access health and disability services or peer support without a diagnosis.[18]

For the doctor, a lack of diagnosis means a lack of guidelines and evidence-based treatments. Doctors often describe a sense of helplessness in the face of undiagnosable suffering.[17,19] Therefore, doctors and patients can share feelings of anxiety, anger and frustration.[20,21]

Patients may have no diagnosis that fully explains their illness experience, but there are often fragments of

explanation that contribute to our understanding of their symptoms.[17,22] Different explanatory fragments can reflect different perspectives, and may include biomedical, psychiatric and psychosocial elements.[23] The challenge for the GP lies in weaving these fragments together and crafting a shared understanding of the problem that the patient and doctor can work with and accept because this leads to better clinical outcomes.[22] For the GP, this means creating an explanation that will 'do for now', while accepting that a more satisfactory diagnosis may emerge over time. This issue is explored further in the case presented at the end of this paper. This can be a difficult and frustrating task for all concerned.[22,24]

The role of psychiatric and psychosocial precipitants: 'Are you saying this is all in my head, doctor?'

One of the most difficult dilemmas in the management of medically unexplained symptoms involves understanding the role of psychiatric illness and psychosocial stress. In contemporary culture, these illnesses are often seen as less real and legitimate than physical illness; they are 'all in the head'.[17] Unfortunately, accepting a psychiatric label also means accepting a deep and unpleasant social stigma.[5] It is not surprising that patients resist the idea of being diagnosed with a psychiatric illness. Nevertheless, comorbidity of medically unexplained symptoms and psychiatric illness is high.[2,7,8] This is not to say that all medically unexplained symptoms have a psychiatric cause, or that psychiatric treatment can cure physical symptoms, but concurrent management can be very helpful.[25]

It is important to help patients understand that the mind and body are interconnected in complex ways, and that holistic care is often essential to improve health. The technique of shifting the focus away from just physical symptoms and biomedical diagnoses, to a more holistic understanding of illness is known as reattribution: a useful technique in primary care.[26]

Types of medically unexplained illness

There are three distinct types of medically unexplained symptoms, which present differently and require different management approaches. While these categories can overlap, it is helpful to consider them individually because they profoundly affect the way the consultation occurs. However, there are also common strategies for managing all medically unexplained illness (*Box 1*).

Elusive illness: Where a significant biomedical diagnosis seems to be 'just around the corner'

In elusive illnesses, symptoms seem to suggest there is a diagnosis, but it cannot be determined at this time. These consultations are characterised by frustration, and fear of 'missing something'. General practice is immersed in uncertainty. At least 5% of patients in general practice have rare diseases,[27] and many people present early, when symptoms are difficult to detect or characterise. We are often in a position to see a patient with significant illness that we are unable to diagnose. We are also unable to 'exclude disease'. Almost any symptom can herald a prodrome of autoimmune disease or an early carcinoma that is undetectable. Patients often find this uncertainty difficult to understand[28] and commonly request 'a blood test to check for everything'.

The challenge for GPs lies in balancing the iatrogenic risk of investigation with the therapeutic risk of missing something important. Statistically, increasing the number of investigations increases the risk of false positives and a cascade of further investigation and treatment that are unnecessary and potentially harmful.[29] By investigating, we also entrench the idea that there is something seriously wrong.[17] Patients can develop a career of medical investigation and treatment.[30]

Strategies for managing elusive illnesses are listed in *Box 2*. Essentially, the goal is harm minimisation and supportive care. Harm minimisation includes regular monitoring for changes

Box 1. Common approaches to managing medically unexplained symptoms

Validation
- Acknowledge that the symptoms are real and distressing
- Acknowledge that medicine has limits and the uncertainty is frustrating

Explanation
- Consider and record physical, psychiatric and psychosocial diagnoses and symptoms
- Craft explanations that include the body and the mind
- Always consider the role of past or current trauma, psychosocial stress and personal vulnerabilities

Coordination of care and advocacy
- Coordinate care to avoid duplication of investigations and exacerbation of iatrogenic harm

Symptom management
- Offer symptom relief and practical support to address disability (eg home help, workplace assessment)
- Encourage physical therapies (eg massage, physiotherapy, hydrotherapy)
- Manage comorbidities as effectively as possible

Broadening the agenda beyond physical symptom management
- Encourage psychological care to address the impact of illness and underlying issues that may exacerbate symptoms
- Address healthy lifestyle goals

Harm minimisation
- Check for new diagnoses when the illnesses changes significantly (eg the emergence of a new symptom) or during a yearly health check

Empathy
- Manage the therapeutic relationship carefully and seek support if it becomes unhelpful

in symptoms, or the emergence of possible diagnoses, while preventing unhelpful cycles of referrals and re-referrals.[31]

Contested illnesses: When every consultation becomes a battleground

Contested illnesses occur when a patient is committed to a particular diagnosis, but the doctor does not agree. These consultations are characterised by conflict,[22] and can become a battleground,[17] described as a 'duet of escalating antagonism'.[32] Patients arrive with a diagnosis they wish to have 'authorised' – an 'illness you have to fight to get'.[18] Common contemporary examples include Lyme disease and multiple chemical sensitivity.

Contested illnesses are more common now that diagnosis has become more democratic. Easy access to online information and support networks have made it easy for people with medically unexplained symptoms to find their preferred diagnosis on the internet.[33] These patients often present with a list of requests for investigations, referrals and treatments, and may have well-developed strategies to obtain these.

Strategies for managing contested illnesses are outlined in *Box 3*. The goal is to maintain the therapeutic relationship between doctor and patient, and develop trust, while holding clear boundaries. This includes ensuring the patient receives good general practice care – it is easy to focus on Lyme disease and miss essential hypertension or generalised anxiety disorder. Contested illnesses are managed best when doctors and patients are able to define some common ground. It is important to clarify areas of agreement and disagreement.[22]

Box 2. Specific approaches to the management of elusive illnesses

Validation

- Acknowledge that rare and early diseases can be difficult to diagnose and may take time
- Acknowledge that many tests will exclude diseases but will not diagnose it
- Acknowledge that many patients have diseases within a discipline, but are without a diagnosis (eg cancer of unknown primary)

Harm minimisation

- Revisit diagnosis regularly. Over time, there will be multiple pieces of information from multiple sources. It may be helpful to have a medical student or registrar take a full, formal history and examination, and present the case
- Monitor mental health. The despair associated with severe, medically unexplained illness is significant, pervasive and risky

Therapeutic relationship

- Acknowledge your own frustration and reiterate your commitment to care for the patient and their family
- Focus on coordinating care to relieve the patient of as much of the burden of managing their disability as possible. It may require some advocacy as agencies may not accept disability without diagnosis

Clinical reasoning

- Pattern recognition is more accurate when patterns are retrieved the same way they are laid down. Describe the case using medical language when writing referrals or notes (eg acute, severe, burning chest pain not associated with exertion or inhalation). If the problem is represented in the notes in the same way it is stored in your memory, the diagnosis is more likely to be triggered and recalled.[38,39]
- 'A clever head trumps a clever test': In the absence of a clear diagnostic hypothesis, consider referral before expensive or potentially harmful investigations
- Patterns exist in different forms in different disciplines. Rare genetic diseases may be recognised by dentists, dermatologists, physiotherapists or general paediatricians on the basis of patterns familiar to them in their own discipline. Therefore, referral to a multidisciplinary team can be critical

Box 3. Specific approaches to the management of contested illnesses

Validation

- Acknowledge what you can accept (eg that the symptoms are real and distressing, that medicine has its limits)
- Acknowledge what you cannot agree on (eg that as a GP, you have no evidence for a particular treatment, that you cannot find sufficient evidence to justify a particular diagnosis)
- Acknowledge that the patient is doing the best they can to manage their illness

Harm minimisation

- Acknowledge that at this time, the medical community has not accumulated sufficient evidence to justify the diagnosis, investigation or treatment the patient is proposing. This may mean that proposed investigations or treatments are unhelpful or unsafe
- Where possible, acknowledge the limitations of self-report and anecdote, and encourage the patient to think critically of treatments that have no objective evidence. This may involving searching the literature to find evidence on behalf of your patient, particularly when they are considering risky or expensive treatments
- Encourage patients to consider the potential for harm, particularly with complementary medicines in those with comorbidities. Health professional and consumer information can be found on websites such as the National Center for Complementary and Integrative Health[40] or the National Prescribing Service (NPS MedicineWise)[41]
- Continue to encourage 'normal' general practice care, including preventive screening, management of comorbidities and lifestyle advice

Therapeutic relationship

- Be prepared to offer support 'within the limits of my discipline'. Do not be reluctant to let patients know when they are exploring options outside your range of expertise
- Recognise when the consultation is degenerating into unhelpful conflict and find a way to break the cycle. Some therapeutic relationships may become unworkable and need to be terminated. Others may require discussion with colleagues

Clinical reasoning

- It may be helpful to think of the illness as a type: 'I do not know that this is Lyme disease, but it is certainly behaving like an infectious disease'. This will help you design appropriate support strategies (encouraging general health, managing fatigue) and referring appropriately in case a different infectious disease is being missed

We should also advocate for our patients and, where possible, protect them from harm. This includes informing them of the risks of expensive and potentially harmful interventions, particularly from specialised clinics overseas that are not subject to Australian regulations.

Chaotic illnesses: Where problems 'go way down to the bottomless depths'

Chaotic illnesses have symptoms that are 'over-explained'; there are many problems and managing one exposes another.

Box 4. Specific approaches to the management of chaotic illnesses

Validation

- Acknowledge that life is overwhelming and often lonely
- Acknowledge that the patient has survived a difficult life
- Ask about, recognise and empathise with childhood trauma issues, and encourage patients to seek support
- Explain how childhood trauma can 'upregulate' the nervous system, and change the structure and function of the brain so that many physical symptoms, including pain, are worsened in adult life.[42,43] Explain clearly and explicitly that this means the pain is 'in the body' as well as 'in the head'
- Explain that you understand there are no simple solutions, but offer what you can

Harm minimisation

- Do not forget preventive care strategies
- Attend to physical and psychological issues separately so that neither are likely to be overlooked. Sometimes, splitting care with another GP can be helpful. This is particularly the case where you are discussing sexual trauma and need to perform an intimate examination like a Pap smear
- Be prepared to acknowledge when a consultation did not go well, and reiterate your commitment to continue to do the best you can
- Protect your patient as much as you can from health professionals who are dismissive or judgemental. Choose 'generalist specialists' like geriatricians or general physicians where possible to minimise the number of therapeutic relationships that need to be managed

Therapeutic relationship

- Find a point of empathy: Many of these patients are frustrating and difficult to help. Understanding their trauma history can help you manage intractable issues that are difficult to address, and manage your own feelings of helplessness
- Accept that regular, scheduled visits can reduce crisis consultations
- Try to keep as few doctors as possible involved in care: It is easy for management to become confused
- Spread the load with a small team: Involve other health professionals (including the practice nurse) and agencies as appropriate.
- Seek your own support if the therapeutic relationship becomes troubled

Clinical reasoning

- Make a clear list of current symptoms, ongoing issues and unresolved problems. Revisit this list if a new symptom occurs to see whether a new disease is emerging

These consultations are characterised by despair and hopelessness in the doctor and patient.

Patients with chaotic illness have troubles that are 'too complex in both medical and social terms for fixing'.[14] Consultations can feel like a whirlpool; it is easy to become caught in a spiral of suffering with no solutions available. Many of these patients are victims of childhood trauma,[34–36] and have complex social needs. Trauma complicates the therapeutic relationship. These patients often find it difficult to trust, and have difficulty establishing and maintaining positive interpersonal relationships.[36] It is therefore not surprising that the consultation dynamics can be challenging.

Strategies for managing chaotic consultations include ensuring there are regular opportunities to conduct an overview of clinical care, documenting all the agencies and health professionals involved in treatment, and ensuring that important preventive activities are performed. A yearly health assessment can help avoid focusing on the cascade of presenting symptoms alone. It is important to record, for each consultation, issues in ongoing care (eg following up results, or monitoring treatment) and presenting symptoms requiring attention before negotiating what can be attempted in a single consultation. Setting a clear agenda minimises the risk of drowning in symptoms without managing the illness effectively. Other strategies for managing chaotic illness are listed in *Box 4*.

Case – Explanatory 'fragments' that may help address the diagnostic dilemma of fatigue

Mia, a university student aged 19 years, presents with fatigue. She lives away from home in a shared house. Her accommodation is unstable and she has spent some time in refuges when her housing has 'fallen through'. Mia has a boyfriend who is verbally abusive, and admits he can become physically violent after alcohol consumption and drug use. Mia has a background of childhood trauma due to sexual and physical abuse from her stepfather. She describes herself as lacking confidence and says she 'attracts one loser after another'. This has become obvious at work, where she describes bullying and harassment from her boss. Her medical history includes glandular fever 5 years ago, irritable bowel syndrome and migraine. She smokes, binge drinks on the weekends and has a poor diet.

Case discussion

The following diagnoses are all possible in this case and all provide potentially helpful directions for care. Note that no one diagnosis explains the whole picture, and it is difficult to prove which diagnosis (if any) accounts for the fatigue. Treatment will require a framework incorporating fragments that are relevant to the patient and helpful to the doctor. The outcome depends on the way such an explanation can help guide treatment and prioritise treatment approaches.

Potential biomedical diagnoses

- Postviral fatigue
- Iron deficiency anaemia secondary to poor nutrition
- Murtagh's 'serious disorders not to be missed' and common masquerades' (eg diabetes, malignancy, thyroid disease, anaemia, etc)[37]
- Poor physical fitness
- Drug and alcohol misuse

Potential psychiatric diagnoses

- Depression
- Anxiety disorder
- Borderline personality disorder

Possible psychosocial formulation

Mia is a survivor of childhood trauma but has continued to replicate unhelpful interpersonal patterns. This has led to poor choices in partners and poor self-esteem, and has exacerbated bullying and harassment at work. She is struggling financially and has poor problem-solving skills, leading to considerable stress and unstable housing. Mia's stress management strategies are often unhealthy and include binge drinking.

Conclusion

Patients with medically unexplained symptoms are often very unwell and require complex care. Strategies include establishing and maintaining a healthy therapeutic relationship, explicitly validating the patient's experience, establishing a common ground explanation, and maximising general health. Harm minimisation strategies include balancing the risks and benefits of investigations and procedures, and advocating for patients at risk of harm from untried investigations or therapies. All patients need support to manage distressing symptoms and the disability that accompanies them. GPs are in a unique position to provide tenacious care for illness in the absence of disease, and for monitoring potential red flags that herald the emergence of a known diagnosis.

Author

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