Navigating invisible illness: Medically unexplained symptoms and the power of narratives

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Background
People with invisible or unexplained illnesses lack an explanation for their suffering. The lack of a coherent narrative limits their capacity to make sense of their experience and inhibits their recovery.

Objectives
To describe common illness narratives and how they are used by doctors and patients to make sense of symptoms. To explore how alternative narratives can be used to empower people who live with ill-defined suffering.

Discussion
Medical consultations are social constructs that follow accepted rules. People describe symptoms that are supposed to drive diagnosis, and then evidence-based protocols enable cure. Diagnosis lends medical authority to a person's illness, enabling access to social goods, including healthcare resources. Without a diagnosis, people can be left without words to make sense of suffering, without community to provide support and without healthcare resources to relieve symptoms. General practitioners (GPs) can provide critical support for people living with uncertain and disabling illness.

LIVING WITH MEDICALLY UNEXPLAINED illness can be difficult – a lonely and deeply challenging journey, with an unknown destination and no map.[1,2] Socially, it can also be isolating. There will never be a fun run for medically unexplained illness. There will never be a transparent ribbon day.

Shorter described medically unexplained illness as an 'ever-changing pas-de-deux' between doctor and patient, with changing expectations, language and diagnostic frameworks.[3] It can be a delicate dance, with a vulnerable patient who is already experiencing considerable discrimination, simply because doctors are unable to find a name for their suffering.[4–6]

The dominant illness story in Western culture is the 'restitution narrative'. It describes the expected course of illness: symptoms are supposed to coalesce into patterns, patterns lead to diagnosis, diagnosis guides evidence-based treatment, and treatment leads to cure.[7] With medically unexplained symptoms, restitution fails, and both doctor and patient have to focus on different goals. They both need to abandon the 'medical mystery' task of diagnosis and pivot to managing symptoms with an uncertain future course. To do so, they need to construct a way of describing and working with the illness that is flexible, empowering and safe.

There are many stories of modern medicine's triumph over illness in public media, so it is unnerving to be left without a diagnosis. Understandably, patients can feel invalidated, dismissed and abandoned when their expected illness narrative fails to surface. In the literature, people describe feeling isolated as families and friends disengage, unable to understand or accommodate their illness.[2,8] Many experienced conflictual and unhelpful relationships with health professionals, describing consultations that feel like a 'tug of war' with each person in the therapeutic relationship trying to drag the other into their point of view.[1,9] Some people can disengage from health services altogether, unable to face a system that invalidates their pain.[6]

Doctors share the expectation of a symptom-diagnosis-protocol-cure narrative arc and can feel impotent and helpless when this narrative fails. As general practitioners (GPs), we can feel increasingly anxious about 'missing something', feeding the understandable anxiety of our patients, who find it difficult to trust us when we can't find 'the answer'.[10–12] We want to help and make a difference, and it is threatening when we cannot find a reason for a person's suffering.

Nobody wants an anonymous illness[13]

What is diagnosis and why is it important?

Diagnosis is not just a sense-making exercise, it is also socially powerful. A disease name gives the doctor a course of action, and patients a word to search, and a community of like-minded people to find. It gives both a 'sketch' of the future and a way of explaining illness to others.[7,14,15] Diagnosis might allow the ill person to adopt the 'sick role', justifying investment of care by family and friends (Box 1).[16] Crucially, they have validation that the illness is not their fault. It is a sad reality of Western culture that people with medically unexplained illness describe preferring a disease with a poor prognosis than living with ill-defined suffering.[17]

Financial supports, like pensions, insurance benefits and other social service payments are often predicated on diagnosis, so people who are unwell must work hard to obtain one.[18] However, not all diagnoses have the same social value. Some diagnoses bring support and empathy while others bring stigma and shame.[19,20] Because of this social weight, it is important that we consider how we make diagnostic decisions. It is relatively straightforward to classify a patient as having diabetes, it is a lot more nuanced to consider using a syndromic term like chronic fatigue syndrome.[21] Even using a term to describe medically unexplained symptoms is challenging.[22,23]

For this reason, GPs often have to find a way to describe illness that is less like botany and more like gardening.[24,25] Like botanical taxonomies, straightforward, well-defined illnesses like fractures or diabetes can be classified into taxonomies that are reliable, valid and clearly guide therapy.

However, when we describe a garden, we might use phrases as shorthand to trigger an image in other people's mind. A Japanese garden and an English cottage garden are fundamentally different, but we might struggle to describe how. In general practice, 'gardening' diagnoses might be syndromes or types of presentations we all recognise: 'she is a survivor of childhood abuse', 'he's a veteran who is caring for his wife with dementia' or 'they are third generation farmers who are struggling financially'. These descriptive fragments are a form of diagnosis too and provide the 'bare bones' of a narrative the doctor and patient can use to ground management strategies and explanatory ideas.

Narrative shipwrecks

When a person experiences a major trauma or chronic illness, it is not just the body that is affected. Illness changes a person's story (Box 2). It might alter their understanding of

Box 1. Common health terms and their definitions[40]

Disease is a pathological process, a deviation from a biological norm, which is known objectively. A disease is usually determined by health professionals.

Illness is an experience of ill-health that is subjective. Sometimes illness exists prior to disease emerging, or may exist without disease. Illness without disease means 'the patient can offer the doctor nothing to satisfy his senses'.[41]

Sickness is 'the external and public mode of unhealth'.[41] It is a social role and describes a negotiated position where the sick person is given support. The recognition that someone is 'sick' usually requires a disease label, otherwise their capacity to secure social goods (eg insurance, social support, health services) is contested.[40] The diagnosis matters – someone with breast cancer, for instance, is far more likely to receive support than a person with inflammatory bowel disease, even if the disability is equivalent. Those with illness and no disease struggle to get support at all.[40]

Syndromes are groups of symptoms that tend to 'run together'. They generally do not have a coherent rationale for the cause of the symptoms or any pathological reasons why they are associated, although multiple theories may be suggested. Syndromes will often incorporate diffuse symptoms, like fatigue, and may over time divide or coalesce.[45]

Box 2. A lived experience narrative of medically unexplained symptoms

When I realised I may always be unwell, I quickly became overwhelmed with a particular type of grief. I mourn the life I thought I would have, the things I used to be able to do, and the people I have lost. I was active, mentally engaged and fulfilled, and always surrounded by people. After a nasty post-viral infection and a series of unidentifiable repercussions, I was left unable to leave the house without being pushed in a wheelchair. I lost my cognitive function - which was intensely frustrating, as I am an intelligent person with an insatiable appetite for knowledge. I had to quit my job, and all I could do was lay down in bed and wait for my partner to come home from work. At my worst, I lost everything that I had felt was a part of my identity. I couldn't paint, read, cook, listen to and make music, be in nature, climb, watch movies and documentaries, play board games, or spend time with my friends. My friends and family initially didn't understand just how sick I was, as they didn't have a name and a box to put me in. When you say 'I have cancer' people make the effort to support you through the illness. When you say 'they don't know what's wrong with me', you are met with silence.

Living with an undiagnosed chronic illness is like feeling your way around a house in the dark. By using your hands to trace the walls, you can identify basic parts of the house such as the light switches, the doorframes, the windows. You can map a general idea of the house but can't define the details. The hard part comes when you want to know the colours of the walls, the curtains, to see the pictures hanging, the doorknobs, the nooks and crannies. This becomes even harder, as my house seems to change all the time. When I think I have figured something out, the walls change again and I am left back where I started. I often feel as though everyone around me has a well-lit house, and I am left alone in the dark. With my GP's patience, empathy, understanding, and relentless fight to try and improve my quality of life, I at least have someone who can guide me through the dark with a little torch. This has allowed me to predict what the sudden changes might be, and to understand how I might manage those changes.

I think it requires a certain degree of empathy and deep feeling to adequately support people like me. The path is never-ending and never linear. Both you and the patient have to be prepared for the day it gets worse again, and be able to support them through the feeling that it may never get better. It is most important to meet the patient where they are at. When they have bad days, weeks, months, acknowledge the hurt, the fatigue, the frustration.

The worst thing I hear is 'it'll get better one day!' This is largely because our conditions are likely to be lifelong, especially when you consider that medicine is not even advanced enough to diagnose us. My GP reiterates that just because we don't have a name for my condition right now, doesn't mean she will stop trying her hardest to make my symptoms as manageable as possible. She celebrates my good days and is there to support me through the incessant grief.

GP, general practitioner

their strengths, weaknesses, values and goals. It is a time when relationships might shift, and the perceptions of their purpose and their future might change.

Arthur Frank describes this as being ‘shipwrecked by the storm of disease’.

> *Stories have to repair the damage that illness has done to the ill person’s sense of where she is in life, and where she may be going. Stories are a way of redrawing maps and finding new destinations.*
>
> (Arthur W Frank, The wounded storyteller: Body, illness, and ethics)

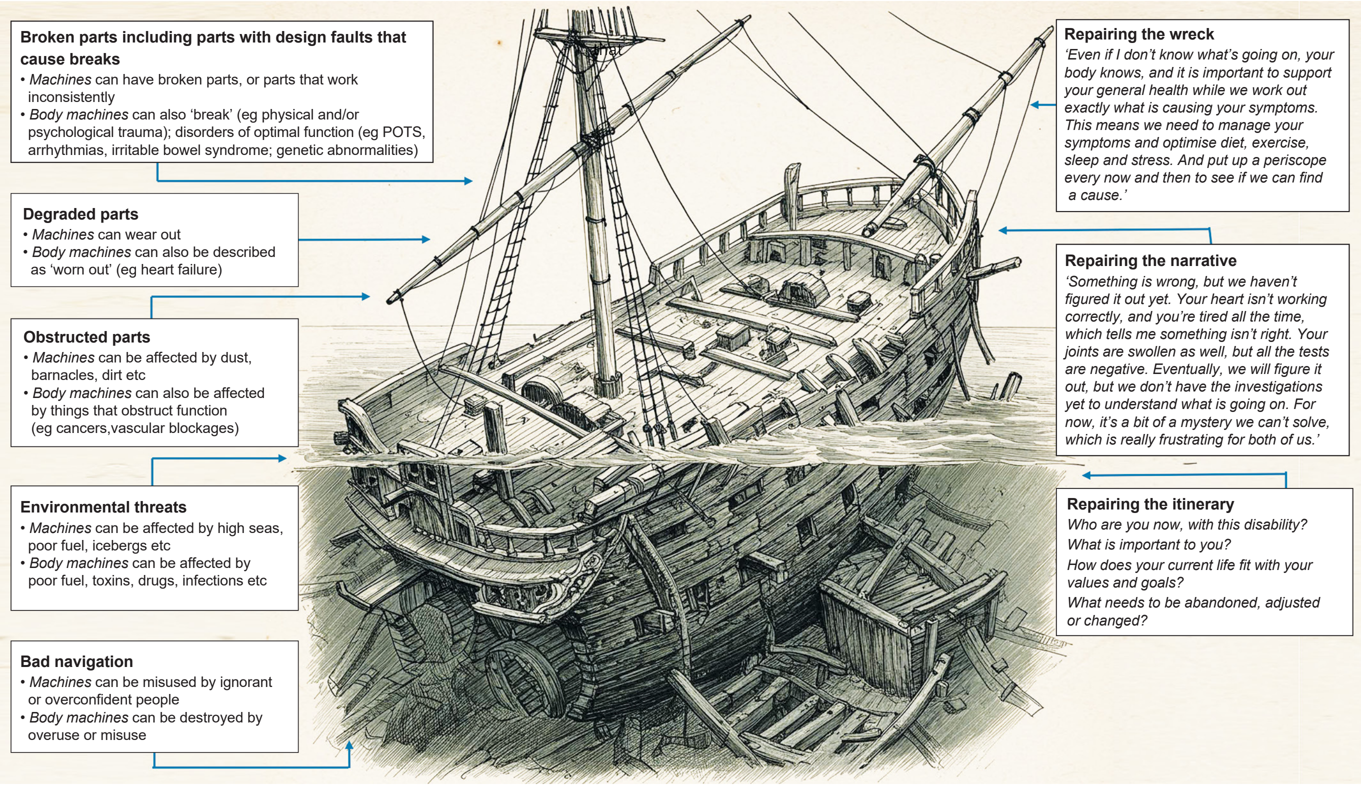
Frank believes that the job of the doctor is to perform repair work, not only on the body, but also the narrative. The work is not always to restore health and help people resume their original journeys, but to help them chart a new course with a changed sense of self. To do so, it is important to understand how they see themselves at a given point in time.

In the following section, we discuss two common ways people understand their own illnesses, and how these can be utilised to promote healing. For both, remember that a map is not the territory.[26] When we explain an illness or a condition, we are using a model that simplifies and approximates what is actually going on. The main issue with medically unexplained illness arises when a doctor’s model and a patient’s model are incompatible. In these cases, it is important to find a way to compromise and come up with a shared narrative that is acceptable to both (Table 1).

The world of the body machine

Bodies are built, developed, modified, repaired and optimised. They degrade and are broken. They respond to their environment – they ‘rust’. They can be fuelled incorrectly or used inappropriately. Parts are even recycled, with transplantation and blood donation. When people conceptualise themselves as a body machine, they will use phrases like the ones in Figure 1.

Body machine explanations include ideas from science. These ideas, phrases and metaphors can be used to help people adjust to the uncertainty of medically unexplained illness. In these cases, a doctor is seen as an ‘engineer’. People can easily believe there is a definite, definable and knowable reason they are unwell. If a diagnosis isn’t found, it is easy to interpret this as incompetence, lack of motivation or disinterest on the part of the doctor. As a GP, it is important to deal with this expectation openly. Helpful metaphors are presented in Table 2.



Broken parts including parts with design faults that cause breaks
- *Machines* can have broken parts, or parts that work inconsistently
- *Body machines* can also ‘break’ (eg physical and/or psychological trauma); disorders of optimal function (eg POTS, arrhythmias, irritable bowel syndrome; genetic abnormalities)

Degraded parts
- *Machines* can wear out
- *Body machines* can also be described as ‘worn out’ (eg heart failure)

Obstructed parts
- *Machines* can be affected by dust, barnacles, dirt etc
- *Body machines* can also be affected by things that obstruct function (eg cancers,vascular blockages)

Environmental threats
- *Machines* can be affected by high seas, poor fuel, icebergs etc
- *Body machines* can be affected by poor fuel, toxins, drugs, infections etc

Bad navigation
- *Machines* can be misused by ignorant or overconfident people
- *Body machines* can be destroyed by overuse or misuse

Repairing the wreck
‘Even if I don’t know what’s going on, your body knows, and it is important to support your general health while we work out exactly what is causing your symptoms. This means we need to manage your symptoms and optimise diet, exercise, sleep and stress. And put up a periscope every now and then to see if we can find a cause.’

Repairing the narrative
‘Something is wrong, but we haven’t figured it out yet. Your heart isn’t working correctly, and you’re tired all the time, which tells me something isn’t right. Your joints are swollen as well, but all the tests are negative. Eventually, we will figure it out, but we don’t have the investigations yet to understand what is going on. For now, it’s a bit of a mystery we can’t solve, which is really frustrating for both of us.’

Repairing the itinerary
Who are you now, with this disability?
What is important to you?
How does your current life fit with your values and goals?
What needs to be abandoned, adjusted or changed?

Figure 1. The ‘narrative shipwreck’ of serious illness. Narrative fragments that might be repaired to construct a ‘recovery’ narrative for a patient with medically unexplained symptoms.

The image in this figure was generated using artificial intelligence (AI) on original instructions from the author.

POTS, postural orthostatic tachycardia syndrome.

Table 1. Some strategies to find common ground with discordant or contested narratives

Stages of negotiation	Theoretical frameworks	Examples of communication
Listen carefully to the patient's narrative, including their requested management (if any)	Roger Neighbour's model of the consultation outlines five stages:[46] 1. Connecting (building rapport) 2. Summarising (understanding, exploring and then summarising the reason for the patient attending and then agreeing on a management plan) 3. Handing over (giving the patient the tools to self-manage) 4. Safety-netting (anticipating likely outcomes and preparing for them) 5. Housekeeping (making sure you are ready to see the next patient) Try to keep to the 'connecting' and 'summarising' phases of the consultation first, exploring experience, and checking your understanding, before moving on. Keeping to the explorative phase of the consultation avoids 'consultation chaos' where both doctor and patient can become bewildered by rapid shifts between exploration and management.	'It sounds like this illness has been going on for a long time, and I'm sure you've tried a lot of things to manage it in the past. Do you mind if we take the time to understand the history? I want to make sure I can make sense of things with you.'
Delay premature closure and resist contesting their beliefs at this point. Instead, try to understand why they have these beliefs by asking curious questions.	Kleinman's illness narrative questions:[47] • What do you call the problem? • What do you think has caused the problem? • Why do you think it started when it did? • What do you think the sickness does? How does it work? • How severe is the sickness? Will it have a long or a short course? • What kind of treatment do you think you should receive? • What are the chief problems the sickness has caused? • What do you fear most about the sickness?	'It's important that I give you the best advice I can, and you've lived with these symptoms, so what do you think is going on?' 'I'm sure lots of people have had suggestions about this illness, what makes sense to you? Do you have any ideas about why it started?' 'What are the things that are the hardest to cope with at the moment? Is there anything you are really worried about in your future?'
Check your understanding of their narrative and make sure that previous doctors have explored Murtagh's 'serious disorders that must not be missed'	Murtagh's safe diagnostic strategy:[48] • What is the probability diagnosis? • What must not be missed? • What are common pitfalls for this problem? • Could the patient have one of the seven masquerades (depression, diabetes, drugs, anaemia, thyroid disorder, spinal dysfunction or urinary tract infection)? • What is the patient trying to tell me (psychosocial issues)?	'I know this is complicated, so do you mind if I summarise what you've told me?' 'I just want to check what's been investigated. Can I run through who've you've seen, and what they thought? What did you think of their suggestions?'
Explore how the illness responds to life events, including stress	Three perspectives on diagnosis:[49] 1. Is there a potential medical or physical diagnosis? 2. Is there a potential psychiatric diagnosis? 3. What is the formulation of the problem (ie why do you think this person is unwell at this time? What are the predisposing, precipitating, perpetuating and protective factors?)	'I just want to make sure I haven't missed anything, so I'm going to ask a few questions. Lots of them won't be relevant to you, but I want to make sure I'm being thorough.' 'Do you have any idea of what might make the symptoms better or worse? Is there any relationship with diet, or exercise, or sleep or stress?'
Summarise what you can agree on and where you may differ in your understanding. If the patient is open to change, consider supplying or seeking information that may counter their existing framework (eg by appropriate investigation)	Motivational interviewing can apply here.[50] People can be 'pre-contemplative' (ie not yet ready to let go of an explanation or intervention). Like interventions for smoking, or other unhelpful behaviours, it is important not to get into an argument, but to 'roll with resistance' and reiterate what you can and can't offer. Offer education but respect refusal or disagreement and simply offer to follow up in the future if this way of thinking becomes helpful or relevant to them.	'Thank you for being so thorough with me. I can see that you have been seriously affected by these symptoms, and they are impacting your life a lot. I agree that … However, I'm not sure about the idea that this is caused by … I'm a GP, so there are some things I can do and some things I can't. I think we should start by exploring 'x' but it's going to take a while before we tackle everything that's going on.'

Table continued on the next page.

Table 1. Some strategies to find common ground with discordant or contested narratives (cont'd)

Stages of negotiation	Theoretical frameworks	Examples of communication
Negotiate a helpful narrative about 'what is going on', understanding that a diagnosis may have a different function for the patient, the doctor and government agencies or health services[49]	Try to craft a narrative that maximises:[49] **Autonomy** – recognising that people have their own views, capacities and perspectives. Listen carefully to the person's story, incorporating their perspectives within the formulation where possible, and managing disagreements respectfully. **Benefit** (while minimising harm) – harm can include misdiagnosis, leading to inappropriate treatment, so this principle includes the need to diagnose safely and accurately. However, there are also harms related to stigma and discrimination that can have a profound impact on a person's life. The welfare of patients is the primary goal of medicine. This principle is particularly important with children: sometimes the benefit is received by others (eg funding for learning support at school benefits parents and teachers) and the long-term harm may be less visible (stigma and poor self-concept for the child), so the potential benefits and harms need to be carefully balanced. **Justice** – overdiagnosis and underdiagnosis are both harmful. These risks can be reduced in vulnerable communities by using appropriate resources, including interpreters and cultural informants.	'It sounds to me like there's some things we know, and some we don't. Unfortunately, we GPs don't have all the answers, but there are some things I think you and I know. We know it is unlikely to be 'x', 'y' or 'z'. We also know that you've tried a lot of treatments, and you've worked really hard to get better. Nevertheless you are still finding these symptoms getting in the way of you living a good life and I agree that these symptoms sound like they might be (autoimmune/ inflammatory/post viral etc), but we may never track down a cause. I think at this point we should stick with your idea and call it what it is: you've got medically unexplainable symptoms that seem to be post viral. Hopefully, we'll have a clearer idea of what's underneath all of this in the future, but for now, we will need to live with the uncertainty and manage the symptoms anyway.'
If the patient has an agenda that you cannot legally or ethically meet, it is important to communicate where your boundaries are, and stick to them, while still offering respectful care within your own limits	The 'FRAYED' framework involves working with contested illnesses, which are situations where you and the patient disagree on treatment. These situations require careful management or the therapeutic relationship degenerates into unhelpful conflict[51] **Fact-finding** – make sure you understand exactly what the patient is asking you to do or provide **Refuse request** – if you are unable to legally or ethically provide their preferred intervention, it is important to say so **Acceptable alternative** – if possible, offer an acceptable alternative (eg delaying an antibiotic prescription or offering an evidence based alternative solution) **Yield or don't yield** – make a decision to give or not give the requested intervention and stick with it **End encounter** **Document diligently**	'It sounds like you are hoping to organise 'x' tests and 'y' medications, is that correct?' 'Given your symptoms, and the reasons you want to organise 'x' and 'y', I'm not able to do this for you. We GPs have strict guidelines about what we can and can't do, and I am not able to help you with these tests. I am very happy to talk about alternatives if you would like me to?'

Table 2. Narrative fragments that describe medically unexplained illness

Narrative	An example explanation
The medical 'cold case'	'The condition you have is like a detective's cold case. We have a whole lot of clues, but we can't work out what really happened yet. I hope that one day we will have better investigations, or more clues, and we will be able to solve the problem, but we can't right now.'
Junk drawer taxonomies	'In nature there are always things that don't fit within their nice, clean classification systems. Scientists usually have a 'junk drawer' classification where they dump all the things that don't fit. Medicine is like that. Sometimes people have illnesses that just don't fit. It doesn't mean we can't treat them, but it does mean they may not have a name.'
Medical 'dark matter'	'We can't make sense of the physics without dark matter, but we don't really know where it is. It's like a gap in the universe we can't explain. Medicine has a lot of them. We know they are there, but we don't understand them yet.'
Unknown vs imaginary	'Just because we can't find out exactly what is going on doesn't mean it's all in your head. There's a difference between something that's unknown and something that's imaginary. It's like the giant squid and the Loch Ness monster. Over time, we've found more and more evidence that the giant squid exists, although we still don't know much about it. As our cameras have improved, we've found less and less evidence for the Loch Ness monster, so it's probably imaginary. You have an illness like a giant squid, not a Loch Ness monster. It's real, it's just unknown.'
Being a pioneer	'Medicine has limits. We are on the edge of what we know with your condition at the moment. Medicine is learning all the time, so I hope we are able to be clearer in the future, but at the moment, it's like we are explorers and we are in an area that is unmapped.'

The world of the body in its ecological context

Health can be seen differently. Rather than a body machine, a human can be seen as a part of a large ecosystem. We thrive, or we do not thrive, according to contexts in which we are placed. With this perspective, a person might become unwell not because their body is broken, but because they are in a biopsychosocial context that is harmful. Discrimination, marginalisation, political alienation, spiritual disconnection and environmental degradation can all influence health. In this, our understanding is enriched by the understandings of First Nations peoples who have shared a variety of ways of knowing and being that incorporate physical, social and spiritual dimension.[27–30]

In this world view, the questions are not about what is wrong with the body machine, but where and how illness occurs. The questions are existential: Where are we ill? Where can healing occur? What form can that healing take? Where is the patient prepared to work? How can we help?

Confronting pirates and sirens at the edge of the universe

There will always be people who want to profit from others' suffering. These 'pirates' use narratives, metaphors and images that suggest scientific evidence to extract money for dubious cures.[31–33] Often they will offer a much-needed diagnostic label and paint the medical profession as ignorant, biased, dismissive or prejudiced, offering an alternative that seems empowering. As GPs, our role is to help protect patients from these 'pirates' by gently creating space for them to reconsider these 'miracle cures'.[34] It is difficult work, and the therapeutic relationship may or may not withstand this form of questioning (Table 1).

Sirens are more subtle. Sirens were mythical sea-creatures who tempted sailors to their deaths. They are often portrayed as using sexual temptations, but they actually used the temptations that people responded to. In the legend of Odysseus, he was lured with the promise of wisdom.[35]

Sirens in modern times are often groups who advocate for new diseases that explain ill-defined problems. Showalter[36] describes how new ways of being sick are being discovered all the time. Because illness without a recognised disease is painful and isolating, there is a tendency to convert diffuse and evolving symptoms with no disease into 'the camouflaged but culturally acceptable language of body illness'.[37] Typically, a scientist or physician (the 'sirens') will propose a theory which is a clear and coherent explanation for the confusing symptoms, and will propose a memorable name. Often there will be a well-known celebrity with the condition, a social media following, television documentaries and various pathographies, all of which 'encourage others to come forward'. In doing so, they drive recognition for the new syndrome. These syndromes offer the promise of validation but actually offer little in terms of successful treatment. They are 'acutely communicable diseases' with a sociocultural vector.[36] Artificial intelligence (AI) chatbots are amplifiers, delivering a personalised message, fed by the social milieu a person accesses. Some of the people with this illness will eventually be diagnosed with a novel disease, or an existing disease that was not diagnosable in its early form. Others will continue to live with unexplainable suffering.

Living with uncertainty

People who live with unexplained illness suffer and are likely to resist disease names that are socially invalidating. It is imperative that GPs address a person's belief that 'you think it is all in my head, don't you doctor?' While physical symptoms can, of course, arise from psychosocial stress and trauma,[38] medically unexplained illness often has multifactorial causes.[39]

GPs can help by affirming the reality of the suffering, seeking to understand a person's own illness narrative and offering helpful alternatives (Table 2). Holding uncertainty is a difficult skill, especially in a data-soaked world where technological solutions seem to be available for every human problem. The doctor–patient relationship is an essential tool in conveying trust, understanding and empathy, as well as ongoing scientific curiosity, so that people are able to live with invisible illnesses and their associated invalidation. Having a narrative that is 'good enough' gives people a life raft until the narrative shipwreck is repaired.

Conclusion

Invisible illness can resolve without a diagnosis being reached, can remain undiagnosed, or can become obvious over time. Qualitatively, it can involve elusive illnesses that can be difficult or take time to diagnose (eg lupus) or can be the result of multiple influences on a person's wellbeing (eg discrimination, environmental degradation, cultural ill-health). Doctors and patients might have different understandings about 'what is going on', and there needs to be some alignment in these illness narratives before effective management can occur.

Key points

- The dominant illness narrative in Western culture is restitution – symptoms lead to diagnosis, which leads to protocol and then cure.
- When there is no diagnosis, patients are left without a story to help make sense of their suffering.
- Without a diagnosis, patients have difficulty accessing resources (eg healthcare), but they also have difficulty describing 'what is going on' to friends, family and self.
- GPs can co-construct an empowering narrative with the patient that enables them to cope with an uncertain future, utilising the patient's existing understanding of the way health and illness occurs.

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