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Opinion

Make diagnostic doubt visible in healthcare

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ABSTRACT

Patients with persistent debilitating symptoms and normal test results can face a diagnostic odyssey that harms both individuals and healthcare systems. Current frameworks use many labels to categorise suffering in these people; one example being 'persistent physical symptoms' (PPS). Though helpful provisional descriptors, these labels can create diagnostic ceilings, leaving patients abandoned without follow-up or hope. This article argues that medicine's difficulty managing uncertainty creates iatrogenic harm, erodes trust, and can drive healthcare avoidance. We propose a paradigm shift from seeking rapid diagnostic closure to legitimising skilled diagnostic doubt through coded clinical positions such as Systematised Nomenclature of Medicine – Clinical Terms (SNOMED CT)'s 'Uncertain diagnosis'. This requires integrated strategies combining advanced diagnostics, mandatory clinician training in uncertainty and communication, named care coordinators, and ring-fenced research funding. Drawing on recent analyses and patient testimony, we contend that making diagnostic doubt visible is not merely an administrative change but an ethical imperative. Transforming abandonment into advocacy through curiosity-driven; continuous care must not be postponed.

Introduction

Clinicians will recognise the problem: the patient with persistent, debilitating symptoms for whom every test returns normal, whose suffering lacks a clear structural explanation and whose care journey results in mutual frustration. As Barnes[1] rightly asserts in her *Future Healthcare Journal* editorial; the scale of this challenge demands urgent, systemic action. The searing testimony compiled by Cheston[2] gives this urgency a human face: individuals whose suffering is so profound they can shower only once a month, and who are so traumatised by clinical encounters that they forgo medical attention even for potentially life-threatening symptoms.

This is the stark reality of what our own group has termed the *diagnostic odyssey*. This results in a costly, exhausting cycle of hope and despair that represents a major, yet largely unaddressed, public health issue.[3] While Barnes's[1] call to improve the management of 'symptom-based disorders' is both timely and necessary, it is insufficient on its own. To focus solely on refining the existing paradigm risks treating a symptom of a deeper crisis: medicine enduring difficulty in constructively managing uncertainty. As Suzanne O'Sullivan has compellingly documented in her award-winning work, the instinct to dismiss what cannot be readily explained often reflects the limitations of our curiosity rather than the absence of disease.[4]

This article argues that the prevailing framework, characterised by a rush to categorise suffering under interchangeable labels such as 'medically unexplained' (MUS), 'enduring', 'somatic' or 'functional' symptoms, can itself become a source of patient harm that fuels system inefficiency. The current preferred term seems to be 'persistent physical symptoms' (PPS). When used as endpoints rather than provisional descriptors, these labels create a *diagnostic ceiling* that leaves patients without a future pathway. They become 'forgotten' patients. Rather than rejecting current reform efforts, we propose a complementary

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paradigm shift: from a system that seeks rapid diagnostic closure to one that legitimises skilled diagnostic doubt, sustains patient-centred enquiry, and dismantles the artificial divide between 'explained' and 'unexplained' illness. Recent evidence demonstrates that patients with persistent physical symptoms are significantly over-represented among high users of healthcare services, incurring substantially greater investigation and total costs compared with other patient groups.[5] With estimated costs to the NHS, individuals and society of over £14 billion annually, the goal is not merely better services for a defined subgroup but an end to the diagnostic abandonment of all forgotten patients, a problem we cannot afford ethically or economically to postpone.[1]

The limits of labels: from clinical tool to instrument of harm

The call for consistent nomenclature, as championed by Barnes,[1] is well-intentioned and essential for commissioning, education, and research. Yet Cheston's[2] qualitative work illustrates how the process of medical labelling, as currently practiced, can inadvertently become an instrument of patient harm. The moment symptoms are deemed 'medically unexplained,' they are often treated as medically unresolvable. Clinical engagement wanes, follow-up ceases, and patients are discharged back to lives of isolation and unmanaged suffering. The experience of our patient author is that some individuals become so frustrated at the lack of progress that they stop seeking medical advice.

This outcome reflects the system-level perspective that many patients and advocacy groups experience as part of the problem rather than the solution. Insights from patient-facing charity discussions repeatedly highlight how labels intended to organise care narrow clinical curiosity and constrain those deserving of further investigation or hope.[6]

Crucially, this framework misrepresents the heterogeneity of the population it seeks to contain. As outlined in the BJGP analysis by Tookman *et al*,[3] umbrella terms such PPS encompass a broad spectrum: functional somatic disorders, undiagnosed rare diseases, atypical presentations of common conditions, and complex multi-system illnesses. Channelling this diversity into a single 'symptom-based disorder' pathway risks diagnostic overshadowing, where the pursuit of rare, evolving, or complex organic causes are prematurely abandoned. As in our article, the patient with Ehlers-Danlos syndrome or a rare autoimmune condition becomes another 'Maureen', lost for years within the system.[3]

Clinical vignette: Maureen's journey

Maureen Sharphouse, a 69-year-old life coach, has documented her story in a book – 'Unhackable Soul'.[7] As a child, she was hypermobile. She experienced frequent joint dislocations, dizziness, digestive problems, pain, and palpitations. These were incorrectly diagnosed as 'growing pains', Fibromyalgia, Raynaud's, Sjogren's Syndrome and Multiple Sclerosis. Her multiple consultations with a range of specialists did not provide the answer. The sense of futility she experienced during her health journey made her reluctant to seek help when new symptoms occurred. Eventually in 2022, after 40 years of misdiagnoses, her own research led to the recognition that her underlying diagnoses was of Ehler-Danlos Syndrome. A confirmed diagnosis has provided validation that her symptoms were real and has facilitated acceptance and appropriate management.

Maureen is not a single case; she is a pattern. The consequences extend beyond inefficiency. As Cheston's[2] work shows, they include active harm. Patients describe encounters so invalidating and distressing that they later avoid healthcare altogether, even when new symptoms may signal life-threatening disease. This catastrophic erosion of trust demonstrates that the current framework does not merely fail to resolve a clinical challenge; it can deepen a human crisis and push the most vulnerable beyond the reach of care. Psychiatry offers an instructive parallel. The longstanding debates over Diagnostic and Statistical Manual of Mental Disorders (DSM) taxonomies and the shift towards dimensional models (such as the Research Domain Criteria framework) reflect a similar struggle: how to categorise suffering when underlying aetiology remains unknown? Psychiatry has learned to hold diagnostic uncertainty while prioritising functional support and containment. This model – tolerating nosological ambiguity alongside active, continuous care – is directly transferable to the patients we describe.

Diagnostic doubt: from stigma to a skilled and coded clinical stance

At the heart of this failure lies the system's difficulty in handling uncertainty. Barnes[1] identifies clinician frustration; Cheston[2] documents the patient's devastation that follows. What remains underdeveloped is the formal recognition of *diagnostic doubt* as a legitimate, temporary, and active clinical position. The ethical imperative to address this gap is well established: as Beauchamp and Childress[8] articulate; the principles of beneficence (doing good) and non-maleficence (avoiding harm) require that we neither abandon patients, nor falsely reassure them when diagnostic certainty eludes us.

Modern healthcare lacks the language, codes, time and often the cultural permission to say, 'I do not know yet'. Physicians may fear professional judgement, or financial penalties, plus reimbursement systems frequently reward diagnostic certainty over the honest admission of uncertainty.[3] As a result, diagnostic doubts are rarely documented. These patients are excluded from research pathways, and the true scale of the problem deepens and remains obscured. We have proposed the formal adoption of coding options such as the SNOMED CT concept '*Uncertain diagnosis*' to make diagnostic uncertainty visible within health systems.[3] Crucially, this is not an admission of failure, but a commitment to ongoing enquiry. It replaces the dead end of 'unexplained' with the open stance of 'not *yet* explained'.

Such a shift demands protected consultation time and continuity of care, both of which our analysis identifies as essential.[3] It requires clinicians to listen, as Cheston's[2] interviewees repeatedly implore and to recognise patients as experts in their own lived experience. Most importantly, it reframes care away from exclusionary reasoning ('nothing found, therefore functional') toward continuous, parallel work: validating and managing distressing symptoms with empathy, while sustaining curiosity about underlying causes. Jadhakhan *et al*'s[5] systematic review reveals that patients with PPS account for a disproportionate level of healthcare resources, highlighting the need for clinical approaches that can hold uncertainty while maintaining therapeutic relationships.

A new model of care for the forgotten patient

Who, then, are the forgotten patients? They are the bedbound individuals in Cheston's[2] research, left without follow-up or support. They are the 'Maureens' navigating years of inconclusive referrals.[3] They are also patients who do not neatly fit PPS constructs but are nonetheless dismissed, often those from marginalised communities whose symptoms are disproportionately attributed to psychological causes.

Forgotten patients are not rare. They are encountered daily across primary care, emergency departments, and outpatient clinics. They routinely fall between service boundaries once diagnostic certainty evaporates. Jadhakhan *et al*[5] found that prevalence estimates for PPS in high users of healthcare range from 2.9% to 76%, with PPS consistently more prevalent in high use groups compared with low use groups. An important nuance is that the challenges we describe – fragmented care, lack of continuity, and the absence of a named coordinator – are not unique to this patient group. Older adults with multimorbidity, people with serious mental illness, and those with rare diseases all experience similar systemic failures. However, patients with persistent unexplained symptoms are disproportionately vulnerable to being 'dropped' entirely

because their lack of a diagnostic label removes them from disease-specific follow-up pathways. Recognising this overlap does not weaken our argument; it reinforces the need for a healthcare system that provides continuous, coordinated navigation for all complex patients, with particular attention to those who fall between diagnostic cracks.

Serving them requires a more courageous and integrated model of care.

A national, integrated strategy

Echoing Barnes's[1] call to action but extending its scope, a funded national PPS strategy is required. One that integrates specialist services with advanced diagnostic pathways, including equitable access to genetic and genomic testing, as demonstrated by undiagnosed disease networks.[3] This needs to be underpinned by clear ethical frameworks that prioritise patient welfare and distributive justice in resource allocation.[8]

Care founded on therapeutic alliance

Services should be designed to prevent traumatising encounters through mandatory clinician training in uncertainty, communication, and bias. Every patient should have a named care coordinator, ensuring no one is 'dropped' from the system and directly addressing the healthcare avoidance documented by Cheston[2] and the fragmented care patterns identified by Jadhakhan *et al.*[5]

Research driven by curiosity

Ring-fenced funding is required for both biomedical research into disease mechanisms and health services research examining why diagnoses are missed. Emerging tools, including artificial intelligence, should be used to explore whether novel disease patterns can be identified from symptom clusters.[3] Research priorities should be informed by patient perspectives on what constitutes meaningful diagnostic progress, particularly given the significant healthcare costs associated with this population.[5] A powerful model for such curiosity-driven research comes from the study of functional neurological symptoms (FNS). Edwards and colleagues[9] proposed a Bayesian mechanistic account of 'hysteria', converting a historically dismissive label into testable hypotheses about attentional set and neurophysiological responses. Subsequent work by Parees *et al*[10] demonstrated that loss of sensory attenuation can be measured empirically in patients with functional movement disorders. This approach does not resolve all uncertainty but transforms diagnostic doubt from a reason for closure into a driver of scientific enquiry. A recent Royal Society meeting on functional medical symptoms precisely showed this opportunity.[11]

Redefining holistic care

Holistic care needs to extend beyond the addition of psychological input to a functional label. It is a whole-person investigation: the simultaneous, integrated consideration of biological, psychological, and social factors without presumptive hierarchy.[3] Such care validates suffering while remaining relentlessly committed to understanding its source.

Call for longer appointments

An important contributor to the problem is a lack of time. Diagnostic doubt requires time to process the patient's symptoms, reflect on the differential possibilities and formulate a management plan. Evidence suggests that while longer consultations cost more per visit, they can bring downstream financial and operational savings. Extending appointment times may reduce the need for costly follow-up appointments, lower hospital referral rates, prevent errors, and keeps patients economically active.[12] A systematic literature review suggests that increased consultation length is associated with more accurate diagnosis of psychological problems.[13] Another factor which may encourage a change in approach is a longer training period for GPs giving them the experience and confidence to express diagnostic doubt.[12]

Conclusion: from abandonment to advocacy, a change we cannot afford to postpone

The challenge of enduring symptoms is a litmus test for a healthcare system's compassion, humility, and scientific rigour. Improving the management of existing diagnostic categories is necessary but, currently, insufficient. Our priority should be to critically re-examine and, where necessary, move beyond categories that inadvertently enable harm.

The way forward lies in replacing premature diagnostic closure with a culture of skilled uncertainty and continuous enquiry. This requires extra thinking time, coding for doubt, investing in advanced diagnostics, training clinicians for empathy and designing systems that do not allow patients to fall into the chasm between 'explained' and 'unexplained.' The ethical foundations of medical practice demand no less.[8] The significant healthcare costs associated with this population underscore the urgency of reform.[1,5]

Our ethical duty is not to explain suffering with convenient labels, but to stand with patients in uncertainty. As Barnes[1] contends, the system cannot afford to delay reform. Investing in a curiosity-driven, continuous model of care offers the most direct path to ending the wasteful diagnostic odyssey, restoring the trust Cheston[2] shows has been shattered, addressing the systemic failures[5] identify, and transforming patient abandonment into patient advocacy. The forgotten, overlooked or abandoned patient with unmet needs must be remembered, and their unanswered questions should become our central concern.

CRediT authorship contribution statement

Myeat Chel: Writing – original draft, Conceptualization. **Minha Rajput-Ray:** Writing – review & editing, Writing – original draft, Conceptualization. **Kiran Jani:** Writing – review & editing, Conceptualization. **Christianne Forrest:** Writing – review & editing, Conceptualization. **Jennifer McCallum:** Writing – review & editing, Writing – original draft, Conceptualization. **Adrian Tookman:** Writing – review & editing, Supervision, Conceptualization. **Steven Walker:** Writing – review & editing, Writing – original draft, Conceptualization.

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