The language of medicine: words as servants and scoundrels

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ABSTRACT – Progress in complex disorders requires clear thinking facilitated by clear language. Clinicians and scientists occasionally become captive to inaccurate language or meaningless terminology and this generates lazy thinking and impedes progress. Has this happened in the case of the functional gastrointestinal disorders (FGIDs), in general, and irritable bowel syndrome (IBS), in particular? FGIDs and, especially IBS, are common illnesses and an important burden on healthcare resources but, in general, have suffered from a lack of progress in the development of safe and effective treatment. Among FGIDs, IBS may be the best defined but significant lapses of accuracy in terminology persist. Among other FGIDs, the situation is more serious; imprecision and lack of consistency in terminology continue to mar progress. This article reviews the chequered history of terminology in this area and concludes that removing the obfuscation generated by poor usage of language should be the first step towards understanding the pathogenesis and improving the management of these, and similar, disorders.

KEY WORDS: functional dyspepsia, functional gastrointestinal disorders, inflammation, irritable bowel syndrome

The perils of phraseology

Understanding complex disorders requires attention to detail and the precise expression of research questions. Nevertheless, clinicians frequently use terms that they actually do not understand or assume they understand but have never actually questioned. Mere repetition of an incorrect concept or inappropriate term seems sufficient to result in its widespread acceptance as dogma and received wisdom, especially if, in the words of Schopenhauer, one 'constantly repeats it with an air of great solemnity'. Thomas Paine encapsulated the dangers of such unquestioned repetition: 'A long habit of not thinking a thing wrong, gives it a superficial appearance of being right'. For example, in a study of physicians' practices and approaches to the surveillance of colonic dysplasia in ulcerative colitis, it was found that the majority of gastroenterologists did not understand the meaning of the word 'dysplasia', even though they used it on a daily basis.[1] While such deficits adversely affect decision making at an individual level, a more global problem is the corruption of medical language to a degree that may confound thinking on clinical guidelines and even healthcare policy. As one moves from disorders which have a clearly defined molecular and/or pathological basis towards those where a precise pathophysiology remains elusive, imprecision in terminology becomes more prevalent. The functional gastrointestinal disorders (FGIDs), and irritable bowel syndrome (IBS) in particular, represent an important illustrative example.

Irritable bowel syndrome

With an estimated community prevalence of 10–15%, IBS can certainly be regarded as a common disorder.[2] IBS is chronic and has a significant impact on quality of life. It affects young people in a productive phase of life, is a cause of work absenteeism and presenteeism, and poses a burden on healthcare resources.[3] A critical perspective on IBS is important for all subspecialists in clinical medicine because it frequently accompanies a diverse range of other medical conditions. Progress in IBS and related conditions has been slow with few advances in understanding or in the development of new options for safe, effective treatment. A clear and precise definition of IBS is clearly a prerequisite to progress. If homogenous and comparable patients are to be entered into clinical trials, then physicians are obliged to develop a definition that can be readily applied and validated. Similarly, if progress is to be made in understanding the cause(s) of IBS, clinical classifications should be capable of yielding subgroups of IBS that share a common pathology, or respond in a predictable manner to a given intervention. Finally, it is most appealing to the clinician and patient alike to have a name, or label, to attach to a symptom or group of symptoms that appear to behave in a certain predictable manner. The dilemma with IBS is that its definition currently relies on symptoms alone and is, therefore, subject to the vagaries intrinsic to how patients express, and doctors interpret, complaints. Has IBS earned its label?

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Have clinicians been captive to terminology that generates imprecise, woolly thinking? Have they abandoned their duty to take a detailed and accurate history? Are they hostage to a language that has retarded research and impeded progress in this area?

At first look, the track record for the definition of IBS does not inspire confidence. Historically, the term 'spastic colitis' was abandoned to distinguish the condition from inflammatory bowel disease (IBD) and because the bowel was considered to be neither inflamed nor in spasm. Ironically, it now appears that a subtle, atypical form of inflammation/immune activation may be present in some patients and many accept that visceral hypersensitivity is a hallmark of the condition and 'spasm' the possible consequence.[4–8] For the patient, the word 'irritable' is an undesirable representation of their complaints; the term 'sensitive' may be a more accurate descriptor. Patients with IBS, not only suffer abdominal pain and discomfort, but are more conscious of their bowels than normal subjects. The fundamental problem may be either one of perception centrally, as demonstrated by brain imaging studies, or one of sensation, peripherally, as evidenced by the almost ubiquitous finding of visceral hypersensitivity in IBS. While dysmotility or 'spasm' may certainly contribute to symptom generation it is far from the whole story and the use of terms such as 'spastic colitis' is, not only pathophysiologically inaccurate, but also reflective of a more paternalistic age when the all-knowing physician developed terminology based on his concept of a disorder, often oblivious to the patient's experience of that very same condition. Paying attention to the patient does pay dividends.

It is noteworthy that, for some patients, symptoms are not localised to the lower bowel and may blend into the realm of another condition which bears the more objectionable name, 'non-ulcer dyspepsia'. How helpful for the sufferer to be described purely in terms of not having something else. For others, the term IBS is completely inadequate as their predominant symptoms, fatigue, fibromyalgia or other poorly explained complaints, are not even referable to the gastrointestinal tract.[9,10] Does this represent co-morbidity or a different end of the spectrum of the same condition? Indeed, the only truly satisfactory component of the term IBS may be the word 'syndrome', signifying a collection of chronic complaints that probably has heterogeneous causes. Thus, the limited repertoire of responses that all organs have to injury ensures that the symptomatic expression of a diversity of fundamental defects is likely to be the same. Similarities and overlaps across somatic syndromes have prompted some to suggest that specific somatic syndromes, such as IBS, are merely an artefact of medical specialisation.[11] Such balkanisation may have served to promote the professional interests of individual specialty groups but may have severely retarded progress; each scurrying after an explanation for those symptoms considered peculiar to their domain while failing to see the commonalities that were before them if only they were to look. It has also been reasonably argued that descriptive terms for poorly defined conditions, like IBS, should be abandoned, because they create an illusion of understanding when, in fact, there is mystery.[12,13]

While there are real concerns with regard to the nature of the precise terminology employed, it is readily conceded that progress has been made in attempting to delineate, on the basis of symptom analysis, a population of patients, labelled as IBS, who share certain demographic, pathophysiological and psychosocial features. While IBS may not be the ideal term to describe these patients, real progress has been made, which is more than can be said for other 'functional' disorders.

Defunctioning the 'functional'

The terms 'functional bowel syndrome', or 'functional gastrointestinal disorders', are especially problematic. Other than the implied, and often inaccurate, connotation of a psychological or 'non-organic' basis, the use of the word functional to describe lower abdominal (functional bowel) or upper abdominal symptoms (functional dyspepsia) is imprecise. These terms have also served to provide 'cover' for the perplexed and busy clinician; attaching the label 'functional' allows them to pigeonhole the patient without further consideration of the symptoms which remain unexplained and ill understood. It is even questionable as to whether so-called functional dyspepsia exists as a separate entity and is more likely a variation on IBS.[14,15] This view is supported by the observation that what passes for IBS in the Orient includes a predominance of upper, and not lower, gastrointestinal symptoms, and that IBS and other 'functional' disorders frequently co-exist.[14–17]

The temptation to develop a catalogue of functional disorders to encompass all unexplained gastrointestinal symptoms has led to the illusion that an unexplained symptom is itself a discrete 'disease'.[18] Is there any evidence that 'functional' bloating or 'functional' heartburn merit this elevation on epidemiological or pathophysiological grounds, or that such categorisation has led to major strides in therapy? The word functional is a refuge for nominalists and should be abandoned.[19] If a name is deemed necessary, the term dysfunctional bowel syndrome would be a more accurate descriptor.

Getting the words right and the right words

Pending the development of a reliable biomarker, the diagnosis of IBS rests entirely on patient history. Since patients cannot be expected to consistently give crisp symptom descriptions, clinicians need to be alert to nuances of speech and subtle variations in meaning of the words used by different patients. The scale of the problem is even greater when one attempts to translate such terminology into another language and/or culture. Furthermore, many studies attest to the unreliability of retrospective recall; patients do not lie; their memories selectively overemphasise the frequency and severity of those symptoms which distress them.[20] With IBS, leading questions may be required. For example, patients frequently find it difficult to express the sense of incomplete evacuation of stool which may be confused with, and described as, constipation. The same symptom may also cause patients to make several trips to the bathroom where they pass formed stool; this may be incorrectly interpreted as diarrhoea.

The sense of incomplete evacuation also needs to be distinguished from tenesmus which usually implies acute inflammation of the rectal mucosa. Clinicians may be surprised to find that neither the Rome nor Manning criteria demand the presence of constipation or diarrhoea.[21,22] However, Rome II did provide a sub-classification of IBS into diarrhoea-, or constipation-predominant IBS (IBS-D and IBS-C), which is potentially misleading as careful (though, sadly, infrequent) assessments of stool weight and volume have not, for the most part, confirmed the presence of either true diarrhoea or constipation in IBS.[21,23–25] Furthermore, patients frequently have alternating bowel symptoms or may undergo transitions between these apparent subtypes.[26] The potential for misdiagnosis is greatest in patients who have persistent, non-alternating symptoms such as true diarrhoea, and it is here that clinicians should be particularly vigilant for alternative explanations that might distinguish these patients from IBS. In this regard, clinicians and clinician investigators alike appear to have been struck by a plague of collective amnesia in regard to the definitions of diarrhoea and constipation which necessitate appropriate changes in stool volume. In the latest iteration of the Rome process, Rome III, this sub-classification, based entirely on the Bristol scale for stool consistency, has been extended to include mixed IBS (IBS-M) and unclassified IBS (IBS-U).[27] Thus, an individual who reports Bristol stool type 1 or 2 on more than 25% of the time would be classified as IBS-C. While this approach simplifies the clinical sub-classification of IBS and has some pathophysiological basis, given the reported associations between Bristol stool scale and colon transit, it still does not satisfy the strict definitions of diarrhoea and constipation. This is not simply an issue of semantics. The recent clinical experience with the serotonin 5-HT_3 antagonist alosetron vividly illustrates the dangers of inaccurate symptom definition and of subclassifications derived thereof. This compound had an anti-diarrhoeal effect and was indicated for diarrhoea-predominant IBS[28]; it soon became apparent that constipation was a real problem, no doubt a consequence of its administration to patients who described 'diarrhoea' but who were not, in reality, so afflicted.[29] It is to be hoped that the new Rome criteria, based on stool consistency, may lead the way to more pathophysiologically appropriate therapies.

Bloating, distension and flatulence are common and distressing symptoms in IBS, yet none of these is even a primary criterion for diagnosis.[27] These poorly understood, difficult to treat, symptoms are likely to remain so if clinicians continue to use these terms as if they were interchangeable; available evidence suggests that bloating may be distinct from distension and neither is the same as fullness; all three are clearly different from flatulence.[30–32] In a typically elegant study, Levitt and colleagues showed that, while flatulence was linked to gas production, bloating and distension were not.[33] Studies on correlations between accurately described complaints of distension, bloating and flatulence, and objective measures such as abdominal volume, gas excretion or transit, while illustrating the pitfalls that await those who take these symptoms at face value, have also provided some insights into their genesis.[30,32] Such studies may open the way towards the inclusion of these symptoms in future descriptions of IBS; thereby, permitting a definition which encompasses complaints which induce considerable distress in the patient and therapeutic despair in the clinician.

Avoiding words of convenience

The term 'medically unexplained symptoms' represents the most honest descriptor for subjective complaints, such as those which feature in IBS. However, where loose thinking prevails, IBS has become a term of convenience. There is, for example, and, perhaps, due to the primacy of pain in the Rome criteria, a tendency to lump all cases of unexplained abdominal pain under IBS. In addition to the obvious importance of making such distinctions in the service of patient welfare and future research, the imperative of rigorous language becomes immediate in a medicolegal context. Thus, increasing recognition of post-infectious IBS and litigation against the food and service industries for cases of chronic abdominal complaints following alleged food poisoning will force expert witnesses into greater precision with language.[33]

Do we need a diagnostic label?

Alluding to the likelihood that an unnamed disease may remain ignored, Richard Asher once observed: 'A rose without a name may smell sweet, but it has far less chance of being smelt'.[34] The main value of the term IBS is that a group of patients can be identified and separated from those with unrelated disorders. They may also be given a reassuring diagnosis and prognosis, and a coherent scientific investigative strategy can be planned. Of the panoply of so-called 'functional' disorders, IBS merits its recognition as a discrete entity. Regardless of unsatisfactory terminology, prospective studies have attested to the integrity of this diagnosis and studies of coherent IBS populations are beginning to improve our understanding of the pathophysiology and management.

A diagnostic label is also desirable for patients. Even for untreatable and inexplicable symptoms, many patients feel frustrated if their physician fails to use a medical descriptor; giving a name to an illness may give some small sense of control to those afflicted. Of course, Asher also pointed out that words and labels may distort descriptions of illnesses and may perpetuate disorders or subsets of disorders whose existence is doubtful.[35] The history of medicine is replete with such terms. As discussed above, IBS-D and IBS-C may be more current examples of misconceptions based on misused words

Recommendations – putting the right word forward

With so much clinical uncertainty and heterogeneity, it may be difficult to see the way forward. A good beginning is to ask the right questions. As with other conditions, the first order of business should be careful clinical documentation and prospective follow up (Table 1). In this way, simple questions can be answered. Is this condition one of relapses and remissions or a

Table 1. Recommendations for putting the right word forward.

- Notwithstanding the unsatisfactory terminology, irritable bowel syndrome (IBS) describes a recognisable entity or group of entities, and merits retention
- The term 'functional' should be abandoned as a descriptor of symptoms
- Prospective studies should be performed to confirm that so-called 'functional' dyspepsia is, in fact, better grouped within IBS
- IBS should not be used as a term of convenience in patients with isolated medically unexplained symptoms such as chronic abdominal pain or isolated diarrhoea
- 'Diarrhoea-predominant' and 'constipation-predominant' IBS need validation in prospective studies to determine the accuracy of the terms, their pathophysiological basis and whether they are truly distinct entities
- Prospective studies should evaluate the diagnostic sensitivity and specificity of individual symptoms and combinations of symptoms eg a sense of incomplete evacuation with altered bowel habit.
- More rigorous description of the phenotype of patient-subsets is needed in prospective studies including those examining disease biomarkers

persistent problem with fluctuations in severity or coping? What are the risk factors for relapse? Is the apparent gender difference in prevalence real, and, if it is, what does this imply? Are putative sub-types discrete entities or part of the same spectrum? One of the more consistent and objective findings, worthy of pursuit, in IBS is visceral hypersensitivity, an observation long familiar to endoscopists. This contrasts with the paucity of data favouring a motility disturbance; yet, current textbooks persist in categorising IBS among motility disorders.[36] It is self-evident that changes in motor activity occur, but this is clearly not the same as dysmotility. Emerging evidence suggests that immune and inflammatory activity appears to be a real feature in IBS and it is conceptually attractive to link it mechanistically with hyperalgaesia (sensitive bowel syndrome).[37] Clearly, not all forms of mucosal inflammation have the potential to lead to IBS; does it depend on host susceptibility? Without adequate phenotypic characterisation of these patients, studies of genotype will be clouded in a confusion of noise. It should come as no surprise that IBS has proven such a minefield for the pursuers of polymorphisms.[38]

Cause and effect

As with most chronic disorders, the clinical phenotype of IBS will probably be found to be dependent on the colliding influences of host susceptibility factors, environmental triggers (which may be microbial), early life experiences, the host response, and modifying influences such as psychological stressors. This implies heterogeneity with variable input from each of the contributory components in different individuals but provides a schema for testable hypotheses. For example, can any clinical feature of IBS be related, over time, to a biomarker of the stress response or the inflammatory cascade? Our lack of understanding of the variations in the IBS phenotype and their relationships to pathophysiology and outcome will continue to restrict progress until genuine efforts to understand the range of presentations are undertaken.

Over a decade ago, IBD was referred to as 'disabling, underfunded and under-researched'.[39] The same could be said today of IBS. The identification of subsets, the definition of mechanisms, and a clear separation of IBD from other conditions helped convince funding agencies in North America and elsewhere to invest in basic and clinical research in IBD. The challenge is the same for IBS. For progress to occur in this syndrome, the phenotype must be defined accurately, even if doing so involves the demise of long-held and much treasured descriptors and classifications. Progress has been made in IBS but a move to the next level will require even greater rigour in our definitions of symptoms, symptom clusters and syndromes. IBS inches forward;[40] the other 'functional' disorders have a long way to go and some may be no more than a mirage. As we refine our terminology we must remain mindful of the primacy of symptoms in this area: '...symptoms demonstrate the inner workings of the defective machine'.[41]

Conveying the message will require clarification of the entities and the scope of the problem, but first, it will require clear language. Onward!

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