Confusion or Clarity?

Nomenclature, Semantics, Jargon, lingo, eponyms, etymology, and terminology in rheumatology

by Prakash Pispati

“What’s in a name?”
This utterly simple four-word question in Shakespeare’s play has no simple answer, certainly not in medical specialities, rheumatology included.
In general, there are two types of people in the world, like males and females, adults and children, vegetarians and nonvegetarians, tea or coffee drinkers, teetotallers and alcoholics, and those who make simple things complex and those who make complex things simple.

Doctors are notorious for making simple things complex. This may be unintentional subconsciously, or even consciously. It may be a professional hazard to think of ourselves as somewhat “superior” to patients in the subconscious hope that they will readily accept and follow our advice, orders, and diktats. We appear always more knowledgeable than we actually are, and hence the lingo we use must sound profound, verbose, at times bombastic and complex, even if unclear to patients. Isn’t it a joke that a doctor’s handwriting is hardly legible? The contents of what we write, even if pregnant with proven medical knowledge, is not necessarily understood by nonmedicos with ease.
For example, a mother came to our clinic with her five-year-old son who had multiple joint pain and swelling. To her anxious inquiry, “What’s the problem, doctor?” I replied sincerely, “juvenile idiopathic arthritis.” Perplexed and more anxious, she posed, “What’s that, doctor?” I was on the defensive; I am still at a loss to explain the term.

This is why we must coin names for what we read, speak, and write that are simple, comprehensible, digestible, assimilable, and then complied with by our patients. After all, we are not almighty gods, even in our clinics.

We rheumatologists seem a lot more humane. We use no complex instruments in our clinical examination. Other specialists may mock us as “primitive,” but I am glad that this is so, for in rheumatology, clinical medicine is supreme. Let’s introspect on medical terms we have coined, designed, and use every day.

**Rheumatology Terminology**

What do we have to answer, at the end of our examination, to the patient’s universal question, “Doctor what is wrong with me? Do I have rheumatism or arthritis?” For centuries, the word “rheumatism” was in vogue, derived from the Greek word rheuma. Fair enough. Then, in the 19th century came in the word “arthritis.” Perfect. What are such terms supposed to convey? Do they give a description of the disease, a specific diagnosis that won’t get mixed up with other diseases, legible to patients and to other doctors, to the pharmacist, to healthcare professionals, to insurance agencies, and even, when necessary, to lawyers and magistrates? If this doesn’t happen, we may well be dealing with the anecdotal “six blind men and the elephant,” each one interpreting his way, confusion galore.

For a standard question that nearly every patient has asked me—“Doctor, do I have rheumatism or arthritis? And what is the difference?”—it’s simple to explain, but with progress we have much more to offer. The word “rheumatism” in its broad sense is meant to convey musculoskeletal symptoms or a related disease. This ancient word is very much in use, even subdivided or in subsets, because rheumatism is meant to suggest soft-tissue rheumatism (i.e., a malady that affects structures outside the joint). Its other subsets over the years have seen names such as myositis, fasciitis, bursitis, tendonitis, tenosynovitis, fibrositis, fibromyositis, and the currently in-fashion fibromyalgia. Contemporary rheumatologists mockingly dismiss “soft-tissue rheumatism” as a waste paper–basket diagnosis. Will the rheumatologist of tomorrow do away with some of the current terms—who knows?

A glossary of rheumatic diseases is well recorded.¹ Let’s look at a few examples. Some words seem to convey exactly what they are supposed to. For example, ankylosing spondylitis, just perfect; other examples: osteoarthritis, polymyalgia rheumatica, or, if you like, relapsing polychondritis. These terms sum up patients’ symptoms, even the disease. In short, easy to spell and pronounce, and comprehensible to doctors, patients, and healthcare professionals alike.

In contrast, we have systemic lupus erythematosus (SLE). Since the 16th century, the word “lupus” has been derived from a word for wolf; but then we added two words to describe systemic symptoms and rash. As a result, this three-word disease comprises 26 letters of the alphabet, is prone to mistaken spellings, is hard for patients to pronounce, and is, indeed, alarming. Isn’t it time we just used the five-letter, one-word “lupus” and discard the other two words? Diehard rheumatologists in their detailed case reports may certainly use the 26-letter,
three-word designation if it pleases them, but let the world formally adopt the word “lupus.” It sounds patient friendly, even if the disease is not. No harm done.

Check out historical documents and you will come across “arthritis deformans” to describe what we understand today as “rheumatoid arthritis.” I believe that the term “arthritis deformans” is apt for this prototype disease. In 1858, Sir Alfred Baring Garrod from England probably thought otherwise, and so he coined “rheumatoid arthritis” (RA). It didn’t seem to carry much weight at that time, and Sir William Osler, in his “Principles and Practice of Medicine” (1909), continued to describe the disease arthritis deformans: “Once established, the disease is rarely curable. Too often it is a slow, but progressive, crippling of the joints, with a disability that makes the disease one of the most terrible of human afflictions.”

In 1923, in a symposium of the Royal Society of Medicine, Sir Archibald Edward Garrod (son of Sir Alfred Baring Garrod), “discussed the fact that several diseases were lumped together as rheumatoid arthritis and said that he was ‘fully aware of its shortcomings .... but this in turn has lost its utility and might be superseded by a better name.’” There followed a discussion among the participants where many suggestions were made, and Kerr Pringle said that the term was “‘a scrapheap for undiagnosed articular affections’ and suggested four forms, while other speakers divided it into six.” Yet, the British Ministry of Health formally accepted the term “rheumatoid arthritis,” and in 1941, the American Rheumatism Association replaced “atrophic arthritis” with “rheumatoid arthritis.” Since then, RA has been used for 90 years unquestioned, even if “arthritis deformans” seems more disease descriptive—or consider “pannus arthritis.” May I submit, most humbly, for a relook by the powers that be, namely, the International Classification of Diseases, Tenth Revision (ICD-10), ACR, EULAR, ILAR, and APLAR?

As another example, the word “podagra” was rechristened “gout.” To this humble rheumatologist, both seem just perfect, short to read, easy to spell, easy to pronounce, and more or less clearly understood by patients the world over. “Gout” sounds cute.

A few other diseases have also been delightfully coined: hypermobility syndrome, tennis elbow or golfer’s elbow, hemophilic arthritis, amyloidosis, reactive arthritis, polymyalgia rheumatica, polymyositis, dermatomyositis, scleroderma, back-pocket sciatica, frozen shoulder, jumper’s knee, carpal tunnel syndrome, traveller’s ankle, erythema nodosum, and psoriatic arthropathy. As against these, we have a few gruesome and complex terms that need to be reviewed: chondrocalcinosis articularis, pseudoxanthoma elasticum, macrodystrophia lipomatososa, and anticardiolipin or antiphospholipid syndrome, with its own confusing and controversial misnomer, “lupus anticoagulant.” And what of “mixed connective tissue disease” (MCTD), which replaced overlap syndrome? The former is supposed to have elements of SLE, RA, dermatomyositis, and scleroderma, all or some of them in varying proportions at different stages. No wonder many young rheumatologists and patients get “mixed up” about MCTD. And what of overlap syndrome? The late Professor Eric Bywaters, in one of his erudite presentations, made fun of MCTD and overlap syndrome and, I remember, he said, “If we don’t understand a complex rheumatic disorder or a mixture of disorders, we simply put it in somebody else’s laps as overlap syndrome.” Will ICD please elucidate?

In pediatric rheumatology we have seen different names from time to time, more or less for the same disease: e.g., juvenile rheumatoid arthritis and juvenile chronic arthritis on the left and right side of the Atlantic on the map, finally giving way to juvenile idiopathic arthritis.
(JIA). Again, to quote Bywaters: “Chronic juvenile polyarthritis is a wide term, Still’s disease is an historical term, juvenile rheumatoid arthritis an exact but misleading term.”8 The current term JIA, rather apologetic, may be in for revision in times to come.

There are rheumatic diseases galore which are named after those who described them eponyms: Just a short list is enough to baffle budding rheumatologists. Regarding acronyms, we have an organization called OMERACT (Outcome Measures in Rheumatology) which elaborates outcome measures. Over the years, we have moved from activities of daily living (ADL) scores, to health assessment questionnaires (HAQ), to disease arthritis scores (DAS28). We now have SLEDAI, BASRI …. complicating our daily routine.

On Reflection

Innovations in medicine, even at breakneck speed, are needed and welcomed. Translational research is certain to impact medical practice. Change is inevitable, but when it gets torrential, the humble clinician and his almighty demanding patient may get perplexed when adapting so quickly. I am reminded here of Alvin Toffler’s bestseller, Future Shock.9 The exponential pace of change leaves the citizen to lag behind as he strives to adapt to the impact of rapid innovations (a recent example: newer devices to subserve the information technology onslaught). What’s the answer? In all such scientific endeavours in biomedicine, with its enormous complexity, elemental simplicity of expression is not to be missed.

Between simplicity and complexity, which should be the numerator and the denominator? Isn’t it time to think, sit up, stand up, and speak up? Let’s begin with just “lupus.” Will the scientists and scholars, high priests and pundits of rheumatology, listen to this humble prayer for a little simplicity in our precious literature? the rheumatologist

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Common Eponyms in Rheumatology

by Prakash Pispati, MD

- Behcet’s syndrome
- Caplan syndrome
- Charcot’s joints
- Churg-Strauss Syndrome
- Cogan’s syndrome
- Crohn’s disease
- DeQuervain’s tenosynovitis
- Dupuytren’s contracture
- Farber’s disease
- Felty’s syndrome
- Francoise syndrome
- Gaucher’s disease
- Handigodu syndrome
- Heberden's nodes
- Henoch-Schönlein purpura
- Hoffa’s disease
- Hughes Syndrome (Antiphospholipid syndrome)
- Jaccoud’s syndrome
- Kashin-Beck disease
- Kawasaki disease
- Leri’s pleonosteosis
- Libman Sachs endocarditis
- Lyme arthritis
- Lofgren syndrome
- Morton’s Metatarsalgia
- Osgood-Schlatter’s disease
- Osler’s nodes
- Paget’s disease
- Pott’s disease
- Reiter’s disease
- Sever’s disease
- Sjogren’s syndrome
- Still’s disease
- Sudeck’s atrophy
- Sweet’s syndrome
Takayasu’s disease
Thiemann’s disease
Tietze syndrome
Wegener’s granulomatosis (Granulomatosis with poliangitis)
Weil’s disease
Werner’s syndrome
Wilson’s disease
Whipple’s disease

A Few Acronyms and Indices in OMERACT

by Prakash Pispati, MD

- HAQ: Health Assessment Questionnaire
- DAS28: Disease Activity Score
- DAS: Psoriatic Arthritis: ACR Core Data Set and Disease Activity Score
- PsARC: Psoriatic Arthritis Response Criteria
- PSAI: Psoriasis Area and Severity Index
- SLEDAI: SLE Disease Activity Score
- BILAG: British Isles Lupus Activity Score
- SLAM: Systemic Lupus Activity Measure
- LAI: Lupus Activity Index
- ECLAM: European Consensus Lupus Activity Measurement
- BASDAI: Bath Ankylosing Spondylitis Disease Activity Index
- BASRI: Bath Ankylosing Spondylitis Radiology Index
- BVAS: Birmingham Vasculitis Activity Score
- VAS: Vasculitis Activity Index
- WOMAC: Western Ontario McMaster Osteoarthritis Questionnaire