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Consensus definitions of disease activity in hidradenitis suppurativa: crossing the semantic gap

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In August 1975, Professor John Tukey, of statistical fame, declared ‘When the right thing can only be measured poorly, it tends to cause the wrong thing to be measured, only because it can be measured well’.¹

This statement effectively encapsulates our current conundrum with regard to disease activity outcome measures in severe hidradenitis suppurativa (HS). Counting inflammatory nodules is the most valid, reliable and objective measure of treatment response that we have available. This does not imply that more effective measures of disease activity and treatment response cannot exist. Kirby *et al.*’s narrative review² in this issue of the *BJD* is a vital first step in the development of consensus definitions of disease flare, which in turn may lead us to more clinically relevant measures of disease activity. The counting of nodules is highly relevant for mild-to-moderate HS in the absence of scarring, tunnel formation and diffuse oedema/lymphoedema. However, in severe disease, nodule count may not accurately reflect changes in disease activity such as reduction in pain, erythema, change in size of nodules, and activity of draining sinuses.

The typical waxing and waning of disease activity in HS is problematic for the assessment of treatment efficacy, and may be a contributor to the high rates of placebo response in randomized trials.³ We are only just beginning to understand the natural history of HS and the expected frequency of flares and relapse in untreated (and treated) populations. This is where consensus definitions of ‘flare’, ‘recurrence’ and ‘relapse’ can aid in the interpretation of future (and retrospective) clinical data. What is known is that, currently, a ‘flare’ is a nebulous, poorly defined concept. The notion varies considerably between patients and physicians, risking miscommunication in the clinic. It is not uncommon for inexperienced physicians seeing a patient with HS for an ‘urgent flare’ to be underwhelmed by the change in the patient’s condition, and the patient to be frustrated by the physicians’ lack of acknowledgement of their worsening condition. This ‘semantic gap’ in itself contributes to the lack of trust many patients with HS express in the healthcare system, leading to delayed

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Conflicts of interest

None to declare.

diagnosis and treatment. Kirby *et al.*'s work² is a vital first step in establishing consensus definitions, but patient viewpoints are vital to ensuring that the existing semantic gap can be bridged. Only with the help of our patients can we strive to appropriately measure outcomes as well as measure the appropriate outcomes.

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