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11th July 2018 Invited editorial for BJD

Authors: Andrew Y FInlay, Francesca Sampogna Words (not including references) = 946

EDITORIAL

What do scores mean? Informed interpretation and clinical judgement are needed

Measurement is the essential heart of high quality daily practice and clinical research. Measurement is essential to assess or monitor our patients, and to deliver evidence-based medicine. Measurement usually generates scores. But what do scores mean, how can informed judgements be based on them, and how can they be appropriately used in the clinic, in research and by licensing authorities?

An article¹ in this month's BJD addresses one "scoring" issue arising from the use of the DLQI, but in so doing raises a range of dilemmas of relevance to all clinical scoring. Rencz et al¹ note that if a patient with psoriasis answers "not relevant" to one or more of the ten DLQI questions, say concerning sport, but actually can't do this activity because their psoriasis is so severe, their DLQI score may not reach a guideline threshold for biologic therapy (i.e. 10). They propose a formula to adjust the score upwards, based on the responses to the other questions. The application of the formula to a real data set revealed that when the formula was applied to 242 psoriasis patients, 8 more (3.3%) reached the threshold of DLQI score 10.¹

There is no measurement that is 'absolute'. Even data describing, say, length (where a meter is defined as the distance light travels in 1 / 299,792,458 sec)² may be influenced by the measurement instrument or observer: clinical data always involves a range of confounding factors. The observer, the measurement device and the patient herself all have unpredictable variability. Clinicians are familiar with concepts of false positive or false negative results and many techniques are used to reduce the impact of this variability in research. But problems arise when the confidence that we place on data with which we are familiar, such as measurement of height, is unthinkingly or inappropriately applied to clinical data with its inherent variability and unfamiliar meaning.

Clinicians learn to interpret clinical scores from published "normal" score ranges, from guidelines and from an unclear osmosis of clinical experience. However, population norms may not be applicable to a specific individual patient, and then in many common situations clinicians may interpret data in different ways, as highlighted by the debate about interpretation of blood pressure values and when therapy should be introduced.³ But how can we interpret a quality of life score and whether its change over time is significant? In order to give clinically useful meaning to quality of life scores, it is possible to define score band descriptors.⁴ But bands, however well validated, apply artificial steps to what is

usually a smooth continuum. So the clinical situation reflected by the close scores immediately on either side of a band dividing point is similar, though by falling into two bands the band description differs. In order to define when the change in a score becomes "significant" to a patient, the Minimal Important Clinical Difference (MCID) can be calculated.^{5,6} But, again, this concept needs to be interpreted with caution. For example, the MCID may in reality be a much smaller score change at the lower end of a score spectrum than at the higher end, even though the user is presented with a single figure apparently to be applied across the range.

So where does this leave the even more confused clinician? The good news is that this leads directly to an affirmation of the value and central place of clinical judgement and wisdom, our special and unique clinical skills. While agreeing with Rencz et al¹ that there may be an issue, perhaps the real problem lies with the guidelines and authorities who may ignore the limits of clinical measurement. What matters is that scores should guide (not mandate) clinical decisions, and that the clinician should be free to use scores within their wider knowledge of what is best for an individual patient.

During the development of the DLQI⁷ in the early 1990s, various scoring methods were considered, including that currently proposed by Rencz et al.¹ We decided against suggesting this adjustment formula because we felt that in a busy clinical setting it would be too complicated for a clinician to calculate the total score. Moreover, a question marked "not relevant" could reflect genuine lack of relevance and correspond to a real zero score, since the patient might be not interested in an activity such as sport, even when fully healthy.

Since then all of the validation and use of the DLQI, reported in thousands of articles, has been based on the simple standard scoring system of adding the individual question scores. Before using the proposed score adjustment formula clinically or in research, a repeat extensive process of validation would have to be carried out. For example, a new score band descriptor study would need to be undertaken, rather than applying the current bands. And applying the proposed formula would most likely cause confusion especially when comparing new studies with the old ones where the first score calculation was used.

So how did the situation arise whereby clinicians may be required to apply a sharp cut-off to a continuum of clinical scores? To try to alter attitudes to the value of considering quality of life, and to subconsciously educate clinicians, a simple message was required.⁸ Hence the proposal that it might be possible to define current severe psoriasis as PASI>10, BSA>10 or DLQI>10 (the "Rule of Tens").⁹ This was always an approximation, based on three inexact measurements. But mandating clinicians to interpret this in an absolute way ignores the reality faced by clinicians daily. Whatever formula is used to calculate DLQI scores, they should be used to help the clinician take the most appropriate decision for individual patients, not used to restrict clinical judgement.

Conflicts of interest

AYF is joint copyright holder of the DLQI. Cardiff University and AYF receive royalties. FS reports no conflict of interest.

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