

SUPPLEMENTARY MATERIAL

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Dermatology Life Quality Index (DLQI): A Paradigm Shift to Patient-Centered Outcomes

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TO THE EDITOR

We thank Dr Nijsten (2012) for his positive comments concerning the ubiquity and impressive track record of the Dermatology Life Quality Index (DLQI), and for agreeing that it is reliable, valid, and easy to use. In the Editorial, attention is drawn to theoretical limitations of the measure and at the same time Skindex is promoted.

It is implied that the questions of the DLQI were "...selected by the researchers based on existing tools, without input from patients". In fact, the questions were derived entirely from the experience of 120 adult patients with a variety of skin diseases (Finlay and Khan, 1994), as acknowledged previously (Nijsten *et al.*, 2006). This aspect of the DLQI has been a major strength of this instrument in that the questions have a high face validity with patients, reflecting the reality of the patient experience in living with skin disease. In contrast to the conclusions reached by Twiss *et al.* (2012), in-depth

interviews with patients with psoriasis revealed that patients considered that all of the important ways in which their lives were affected by psoriasis were covered by the DLQI questions (Safikhani *et al.*, 2011). Scrutiny of the DLQI in its use in many hundreds of research studies has unfolded new properties or reconfirmed its original concepts (Basra *et al.*, 2008).

Nijsten states that the Item Response Theory (IRT) methodology is considered the "gold standard" in the development of Health-Related Quality of Life (HRQoL) instruments, and we agree that it is important to use the highest quality psychometric techniques such as the IRT. However, this does not mean that the Classical Test Theory (CTT) is wrong; it is still being used for the development and validation of new HRQoL instruments (Evers *et al.*, 2008), and the person and item statistics derived from these two measurement models are comparable (Xitao, 1998; Lin, 2008).

CTT has the advantage that data are not fitted to a predetermined mathematical model, and thus assumptions do not need to be met before developing this framework, and a disadvantage of Rasch analysis is the need for larger sample sizes. Skindex-29 was created using the CTT and does not fit the Rasch model (though Skindex-17 does); thus, it is not possible to say from a methodological viewpoint whether it is worse or better than the DLQI. Although Nijsten quotes evidence against the unidimensionality of the DLQI (Nijsten *et al.*, 2006), there are other reports supporting its unidimensional nature and hence the use of a summary score (Mork *et al.*, 2002; Lennox and Leahy, 2004; Mazzotti *et al.*, 2005; Takahashi *et al.*, 2006; He *et al.*, 2011).

Nijsten has suggested a "generation" classification of HRQoL tools, but not every quality-of-life (QoL) tool fits neatly into this labeling scheme. Although by being the first dermatology-specific tool the DLQI is by definition "first generation", its questions were entirely based on the views of

Abbreviations: CTT, Classical Test Theory; DLQI, Dermatology Life Quality Index; HRQoL, Health-Related Quality of Life; IRT, Item Response Theory; QoL, quality of life

patients, apparently not a “first-generation” characteristic.

One aspect of the development of the DLQI, not directly addressed in the Editorial, is that this has been a successful example of translational research. A concept developed in a research setting has moved into daily clinical practice. In the UK, where it is a requirement that the DLQI be used to support decisions concerning biologics in psoriasis, clinicians are familiar with the measure and use it in other clinical settings to inform the consultation and to support decisions. The original stated aim (Finlay and Khan, 1994) was for the DLQI to be useful in routine daily clinical practice.

As implied by Nijsten (2012), clinical practice and physician habits are notoriously difficult to influence. There is often a lag of many years after the introduction of new treatments or ideas before clinicians' behavior changes. After two decades, we are finally beginning to see an awareness of the importance of QoL issues and of the value of their measurement in clinical dermatology practice. To gain acceptance of new concepts or new ways of thinking, messages have to be very simple and techniques have to be very easy to use. The DLQI was deliberately designed to be simple to use and to score. Moreover, it has a very simple method of score interpretation (>10=very severe impact; Hongbo et al., 2005).

An equally important aspect in the process of promoting a shift in thinking among clinicians is the need for consistency in the methodology. The DLQI in use today is exactly the same as that first published in 1994 (Finlay and Khan, 1994). Although this may be a weakness (Nijsten, 2012), it has also been essential in minimizing confusion in the minds of clinicians and in facilitating that shift from publication to actual use in the clinic. Although improving the validity and utility of Skindex, the availability of subsequent versions (-61, -29, -17, -16) may have left clinicians confused about which is

the best version to use; indeed, the Editorial states that two of these versions are the preferred instrument.

Nijsten raises concerns about the theoretical limitations of the DLQI as “the continued use of this instrument may have far-reaching clinical and financial consequences.” We are not aware of any evidence to suggest that the continued use of the DLQI in policy and treatment decisions has been to the detriment of dermatological patients. In fact, the opposite has been the reality.

We agree that all techniques in medicine should be critically reviewed, and that it is important that improved techniques be developed. The fundamental purpose of our research has been to enhance the awareness of QoL issues in daily clinical practice. This message has still so far only reached a small fraction of dermatologists worldwide: we wish Dr Nijsten and colleagues success in their continuing valuable contributions toward this aim. The DLQI and Skindex have different strengths, and both researchers and clinicians benefit from being able to choose which best meets their needs.

CONFLICT OF INTEREST

AYF is a joint copyright owner of the DLQI. Cardiff University gains some income from the use of the DLQI.

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