

Future Directions in Dermatology Quality of Life Measures

Laura K. DeLong, MD, MPH^{a,b}, Suephy C. Chen, MD, MS^{b,c,*}

KEYWORDS

- Dermatology health status • Clinical significance
- Guidelines • Quality of life

Within the last few decades, outcomes research, and in particular quality of life (QoL) outcomes research, has become integrated into clinical and research practices. This change has transformed medicine from an old model, which had an emphasis on targeting objective measures such as blood pressure, to a new model where subjective measures such as QoL are of importance.¹ Many dermatologic conditions are associated with clinical findings and symptoms that can negatively impact health-related QoL. This change in QoL is often the reason for which care is sought. Furthermore, the experience of health-related QoL is different for each person. This experience may be related to the patient's disease or treatment, and it may incorporate differing cultural and historical experiences. For this reason, treatments are not only targeted to impact objective findings, but also to those that are more subjective such as itch, which is often the most bothersome aspect of the disease to the patient. Said another way, dermatologic diseases carry significant psychosocial burden and morbidity from appearance and impact on symptoms, function, and emotion, with few cases of mortality. Therefore, it is important within dermatology to address and incorporate QoL into clinical and research practices.

Fortunately, much work has been performed in the development and application of different types of QoL measures in dermatology. The paradigm of generic health versus skin-specific versus condition-specific health status instruments has been reviewed extensively elsewhere.^{2,3} Similarly, criteria as to how to choose a particular health status QoL instruments have been explored in other well-developed articles.^{4,5}

The next generation of dermatology QoL work, in the authors' opinion, should focus not only on validating health status instruments and be rigorously tested for psychometric properties, but also concentrate on methods to assign clinical meaning to these instruments and to explore guidelines for the development of disease-specific measures. Additionally, less work has been performed on health preference measures of QoL (vs health status measures) that can be incorporated into cost-effectiveness analyses. In this atmosphere of limited health care resources, health policymakers will be forced to curtail certain treatments; dermatology needs to be able to join in these discussions by providing quantifiable metrics to incorporate the QoL improvement treatments offer. More specifically, outcomes researchers need to explore approaches to estimate preference-based QoL measures that are not as cumbersome as current

The authors have nothing to disclose.

^a Department of Dermatology, Emory University School of Medicine, Emory Clinic, Building A, 1365 Clifton Road Northeast Suite 1100, Atlanta, GA 30322, USA

^b Division of Dermatology, Atlanta Veterans Affairs Medical Center, Decatur, GA 30322, USA

^c Department of Dermatology, Emory University, 101 Woodruff Circle, Atlanta, GA 30322, USA

* Corresponding author. Department of Dermatology, Emory University, 101 Woodruff Circle, Atlanta, GA 30322.

E-mail address: schen2@emory.edu

Dermatol Clin 30 (2012) 343–347

doi:10.1016/j.det.2011.11.005

0733-8635/12/\$ – see front matter © 2012 Published by Elsevier Inc.

methods to maximize available cost-effectiveness analyses.

CLINICAL SIGNIFICANCE OF QoL MEASURES

The principles of evidence-based medicine are used increasingly in dermatology to guide clinical practice and resource allocation. With outcomes research blossoming, more emphasis is being placed on the results of these studies to inform clinical practice. The use of valid and clinically meaningful patient outcomes measures is vitally important to reaching this goal with quality and success. Therefore, there is a need to standardize scoring systems for measuring disease severity and other patient outcomes in the clinical trial setting. Lack of standardization and validity of measures can prohibit the meaningful interpretation of individual studies. Furthermore, wide variations of trial methodology that limit the comparison of data from different sources impact the production of therapy guidelines, compendiums of evidence, and systematic reviews. It has been noted that within the literature, there are almost as many scales as there are trials.⁶ Signs and symptoms are frequently mixed up together, and patient-centered outcomes measures, despite the awareness of QoL outcomes, seem to be neglected by an urge to measure objective signs. The clinical meaning of percentage changes in continuous objective scales will always be difficult to interpret and need to be interpreted in conjunction with other outcome measures, as in practice it is the patient who is treated and not the signs of the disease. Despite the known importance, QoL is assessed in a surprising minority of trials.

INTERPRETING RESULTS FROM OUTCOMES DATA

Many health related QoL studies have focused on cross-sectional comparisons between groups, but great interest lies in the assessment of intraindividual change over time. To demonstrate the value and success of various treatments and care protocols, the research needs to show that the observed changes in patients' outcomes are important and clinically substantial. Most studies attempt to assess clinical efficacy of a given intervention compared with another by making group comparisons and evaluating for statistically significant differences. Unfortunately, statistical significance does not in itself provide concise information about a given intervention's clinically meaningful effects.

One approach is to assign clinical meaning to bands of scores of the QoL instrument such that 1 band of scores can be interpreted to have

a particular amount of QoL impact. Hongbo and colleagues⁷ were among the first to apply this approach in dermatology. By anchoring the QOL scored to a global question of overall impairment to QOL, they were able to assign clinical meaning to bands of scores of the Dermatology Life Quality Index; for example, scores from 0 to 10 represented "no to a small QoL impact." Thus, a change in score from 12 to 8 may represent a clinically meaningful change, while a change from 10 to 6 would not be clinically meaningful even if it were statistically significantly different. Other groups have applied this concept to the Skindex. The authors refer readers to Rogers' article in this issue for a thorough review.

While using clinical bands of scores is a useful first step to interpreting QoL instruments, those methods do not provide information for the minimally important difference (MID), that is the smallest change in QoL scores that the patients perceive is important. This change may be within a clinical band, or may straddle between 2 bands. This determination of the magnitude of intra-individual change necessary to establish clinical relevance remains to be determined for most measures. The methods for linking statistical evaluations and clinically meaningful standards for change are areas of future research. Although there are no agreed upon standards, the question of how to meaningfully interpret changes in QoL scales can be addressed with many existing methods.^{8,9} The authors outline several approaches and examples that future investigators may want to explore for existing validated dermatology measures.

Anchor-Based Approach for MID

One approach to establish the MID is to compare with an independent standard or anchor that is itself interpretable and to which the instrument under investigation bears at least a moderate correlation.¹⁰ Possible anchors for dermatology include changes in global ratings by subjects, change from systemic or high-potency topical treatments to low-potency topical maintenance treatments, fewer office visits, fewer missed days from work, or other improved measures of function. In this research, there is a shift from a focus on the mean difference to the difference in the proportion of patients who experience an improvement greater than the MID in the treatment and control groups. Said in another way, if the treatment is effective, more treated than control patients will show an improvement.¹⁰

Reliable Change Index

The reliable change index (RCI) calculates whether the change in score from before to after treatment

Download English Version:

<https://daneshyari.com/en/article/3195667>

Download Persian Version:

<https://daneshyari.com/article/3195667>

[Daneshyari.com](https://daneshyari.com)