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AYF is joint copyright owner of the PDI, ADI, CADI, DLQI, CDLQI, FDLQI, IDQoL, DFI, PFI-14, FROM-16 and MLCDP. Cardiff University and AYF receive royalties.

Abstract

Background

Developing and managing measures of Quality of Life (QoL) requires attention to a range of broader concepts, in addition to meeting validation requirements.

Objectives

The aim of this review is to describe development and experience in Cardiff of these concepts and to inform users of Cardiff quality of life tools of aspects of their origin, for the benefit of developers of novel QoL measures or other patient reported outcome measures.

Methods

Publications from the Cardiff team over the last three decades are used to illustrate descriptions of concepts involved in developing and managing QoL measures.

Results

The concepts are grouped into three main themes: A) Design of tools: measurement ability turns ideas into science, QoL measurement based on patient experience, the need for tools to be clinically practical and useful with meaningful scores, different ages need tailored tools. B) Practical management of tools: enabling ease of access, maintenance of single version, translation validity, enabling access to post publication experience and further validation. C) Promoting wider understanding of QoL: examples include educate thinking with disease severity definition; heighten awareness of broader burden, family impact and the time dimension.

Conclusion

The development and management of QoL and other outcome measures involves attention to a wide range of other issues, in addition to meeting validation requirements.

Key words

Quality of Life, concepts, measurement development, design, validation, skin disease burden

Introduction

A prime focus in quality of life (QoL) measurement is on the appropriate validation of new measures.^{1,2,3} But questionnaire validation takes place in a much broader framework of concept development and tool management, involving wider issues that are seldom discussed. An understanding of the motivations behind the creation of a QoL measurement tool and how concepts around QoL measurement have developed provides a fuller appreciation of a QoL measure.

The aim of this review is to describe the development of the conceptual framework within which some commonly used QoL measures have been created, the motivations behind their creation and the strategies used to manage these tools. The experience of the Cardiff team is described. This background information provides novel transparency and also gives an “inside” perspective: this may be of interest to those using such measures and be of value in informing developers of new tools. Fig 1(a) depicts the basic outline of the creation of a new QoL measure: the surrounding broader framework and concepts, encompassing validation, are depicted in Fig 1(b). Some of the concepts described are seldom discussed but may be crucial in determining whether a tool is actually used. Others are either closely related to or are an integral part of validation of a new measure, but are presented here within this broader framework.

Insert Figure 1(**1a and 1b**) here.

Design of QoL measurement tools

Once you can measure it, it can become a science

Years ago there were detailed descriptions^{4,5} of the impact of skin diseases on QoL. But apart from stating that this impact existed, there was little more that could be done. In the scientific world, things that cannot be measured are often accorded little importance: to make people properly aware of this QoL impact and to consider what can be done to positively influence it, it was necessary to be able to measure it and to turn a descriptive aspect of clinical medicine into a science.

Encouraged by an editorial⁶ and influenced to measure all aspects of skin,⁷ we developed the first disease specific QoL measure in dermatology, the Psoriasis Disability Index.^{8,9} We interviewed large numbers of patients with psoriasis,

asked them what impact it was having on their lives, and distilled the answers into a series of questions. Crucially the answer to each question was scored and then summed to give an overall score. This was then used to provide the first demonstration that, overall, QoL was improved by inpatient therapy for psoriasis.⁸ That study also identified some patients whose QoL was worse after inpatient treatment: this information could have been crucial in informing clinical decisions over those patients, illustrating the powerful clinical potential of being able to measure QoL. This experience encouraged us to create another disease specific measure, the Cardiff Acne Disability Index.^{10,11}

Measurement of QoL solely based on patient experience

Clinicians may believe they have more insight into a disease and its impact than those affected. After all, clinicians see large numbers of patients with a particular condition, understand about its impact and so could have a wider knowledge of the disease than any individual patient. Some measures have been based on a mixture of clinician opinion, literature review and patient input.¹² Information from these other sources may be important. However, for the measures we have created the question content has always been based solely on the actual experiences of patients. One of the reasons that the DLQI has been so widely accepted worldwide may be because of this question basis.¹³ The information on which a measure is based is an important additional validation characteristic not included in some reviews.²

The need to make measurement of QoL clinically practical

Disease specific measures such as the PDI or CADI could be created for every skin disease. However this would result in a confusing array of measures for the large number of different skin diseases, impractical for any clinician to use routinely. The basic aspects of people's lives affected by skin disease are largely the same, though with different emphases. This raised the prospect of developing a single questionnaire that could be used in patients with any skin disease, a crucial aspect of making QoL measurement practical in the clinic.

By the 1980's there were several generic QoL or Health-Related QoL (HRQOL measures) designed for use across all of medicine, such as the Sickness Impact Profile and the Short Form-36. Many were long and so unsuitable for routine use in a busy clinic, but could be used for research to measure QoL in dermatology.¹⁴ However if QoL measurement was ever going to be carried out routinely in a clinic, it was essential that the measure be short, easy to understand, able to be completed unaided and have a simple method of scoring.

These practical considerations were at the heart of the design of the Dermatology Life Quality Index (DLQI).¹⁵ This measure was used extensively as a patient reported outcome measure in clinical research¹⁶ before it was eventually accepted as a routine clinical measure.

Efforts to produce the DLQI were also driven by a desire to be the first to create such a specialty specific measure. It was several years after first presentation¹⁷ that other measures with the same aim were published.^{18,19} The novelty of the concept of measuring QoL across skin disease was emphasised by its initial publication rejection.²⁰

Adding “usefulness” to measures: score meaning, conversion of data, e-usage.

For most HRQoL measures there is no guidance over what the scores mean clinically, or how to interpret score change. These measures may be used in a research setting, but, without meaning, they are of little value clinically.

The creation of validated score meaning bands for the DLQI was a critical step:²¹ for example a score from 11 to 20 means the skin disease ‘is having a very large effect on the quality of life of the patient’. This transformed the DLQI from being confined to research to being a tool that a clinician could actually use and understand.²² The knowledge of what constitutes a Minimally Clinically Important Difference (for the DLQI a score change of four)²³ also allows clinicians and researchers to interpret the clinical meaning of a change in score.

A more recent “added usefulness” study has demonstrated how DLQI scores of a population of subjects can be converted to EQ5D utility scores.²⁴ This has potential for enhancing the value of existing large databases of DLQI information.

HRQoL measures are frequently administered “on screen’ on the unproven assumption that subjects will respond to a questionnaire administered via tablet or smart phone in the same way as on paper. The validity of administering the DLQI in an app has now been demonstrated,²⁵ providing reassurance to users of the DLQI that this mode of application will not invalidate results.

Addressing the needs of different ages

Most QoL measures have been developed for adults, with consideration given only later to infants, children, teenagers and the elderly. The lives of people at

these ages are obviously very different and so separate measures are needed. The issues are complex: surrogate measures have to be used for infants, the lives of children are very different at different ages, and the varying ages of development of teenagers need to be taken into account in tool design: this has been highlighted comparing the use of the DLQI and CDLQI in 16-18 year olds.²⁶

The mode of administration of a questionnaire may have an impact on its use and usefulness. The CDLQI was made more fun for younger children by adding cartoons to the standard text:²⁷ there is great potential for further such development with e-delivery.

Practical management of QoL tools

The need to ensure ease of access: constantly updated website

Instant open access is essential for a measure to be useful to clinicians or researchers. Since 1995, the Cardiff University Dermatology Department website has provided all of the QoL measures in full, along with all approved translations, scoring information and references.²⁸ If online information is complemented by rapid response communication with the measure originators, users are able to take fully informed decisions about which measures are best for their use.

The need to maintain a single version of a measure

The wording of any questionnaire designed to measure QoL must always be exactly the same. Validity, comparability of scores and reliability are all annulled if the words change. The protection of copyright law²⁹ is critical in maintaining the integrity and value of a questionnaire, while not inhibiting the clinical use of a measure. Hundreds of requests to alter DLQI wording have been refused: the cumulative effect would have been to cause confusion and rejection amongst potential users. The reality for clinicians is that choice over QoL measures leads to confusion: one strategy therefore is to try to add “usefulness” to measures (despite any faults) rather than producing different versions.

The need to ensure translation validity, a single validated translation and cultural appropriateness

It is unusual for a single one-way translation to be totally accurate: subtle differences between languages, mistakes and differences of opinion are common.

A validated process is needed with a minimum of two independent translators creating one forward translation, then coming together to reach an agreed translation. Then third and fourth independent translators back translate to the original language to be reviewed by the original authors. This nearly always reveals inconsistencies: the process is repeated until the translation is as accurate as possible. All translations of the Cardiff University measures have gone through this process before being placed online.²⁸

The translation process results in an almost exact language translation. However there is also a need for cultural adaptation. This is to ensure that questions are relevant, or modified to ensure appropriateness in the culture of the country of use. This involves testing the questionnaire with local subjects and incorporating feedback. Even where validated translation and cultural adaptation has been carried out, this does not necessarily ensure that scores will have exactly the same meaning between different countries.³⁰ This assumption is often made, especially in multinational studies, and is an unresolved issue of relevance to all HRQoL measures.

If more than one centre independently translates a measure there is the likelihood that two version of the measure, probably with slight differences of meaning, could circulate causing great confusion. The likelihood of this can be reduced by having the validated translation for each country accessible online and by not giving permission for second translations. Where errors are pointed out they can be checked and corrected where appropriate.

Summarising experience with tools, for easy access to validation information

It is helpful if QoL instrument developers summarise and report on the later published experience of their use, though this seldom happens. In reviews parallel to the “Post-Marketing” surveys of new therapies, we have reported on 10-20 years experience of the PDI,³¹ DLQI,^{16,32} CDLQI,³³ IDQoL³⁴ and DFI.³⁵ These summaries bring together many aspects of validation of these measures that would otherwise remain scattered and unidentified in the literature. They also highlight aspects of validation that still need to be addressed.

There are many anecdotal reports of the use of QoL measures in routine clinical practice but hardly any publications³⁶ describing or assessing this use. The EADV Task Force on Quality of Life has given an expert opinion statement describing the potential benefits of routine use of QoL measures.³⁷

Promoting wider understanding of QoL and its measurement

There are ways in which developers of QoL measures may enhance wider understanding of the use of these tools. Examples include the Rule of Tens, a focus on family impact and an emphasis on the long-term effects of skin disease on people's lives.

Creating a simple definition to educate thinking about QoL: The Rule of Tens

The Rule of Tens (Fig 2) was the first proposal to incorporate a QoL measure in a disease severity definition.³⁸ There were several underlying motivations. The "Rule" aimed to alter thinking about QoL, demonstrating that it is of equal importance in assessing disease severity as traditional sign based measures. Its acceptance would lead to more familiarity with and publicity for the DLQI. The Rule would educate clinicians that DLQI scores mean something and that 'over 10' means 'a very large effect on QoL'.²¹ The Rule was also proposed at a time when the National Institute for Clinical Excellence in the UK were initially considering a much higher cut off DLQI score threshold for use of biologics in psoriasis: the Rule contributed to achieving the objective of lowering this threshold. Many national guidelines now incorporate the Rule of Tens or variations on this Rule, thereby achieving the original aims.³⁹

Insert Figure 2 here

Heightening awareness of the broader burden of skin disease: the family impact

Attention to the impact of skin disease on QoL inevitably focussed first on the patient experience.^{14,15,18} However skin disease also impacts on partners or other family members. The term "The Greater Patient" was proposed to encourage awareness of this:⁴⁰ it describes the immediate family unit surrounding the patient, whose lives may also be disrupted by the disease (Fig 3).

Most obviously, a child with atopic dermatitis will have parents whose lives are also disrupted.⁴¹ As little attention is paid to a problem unless it can be measured, the Dermatitis Family Impact questionnaire⁴² was created to measure the impact of childhood atopic dermatitis on the QoL of other family members. The similar impact of psoriasis⁴³ can now be captured by the Psoriasis Family Impact-14⁴⁴ and the Family Dermatology Life Quality Index (FDLQI)^{45,46} can be used to assess the impact across any skin disease.

This partner and family impact of disease occurs across the whole of medicine.⁴⁷ As there was no generic questionnaire (equivalent to the EQ5D or SF-36) for families, a generic measure was developed, derived from 26 specialties, the Family Reported Outcome Measure (FROM-16).⁴⁸ By allowing the impact on families to be measured, further research is encouraged, hopefully eventually resulting in evidence based methods to mitigate the secondary impact on the family.

Understanding the broader burden of skin disease: the time dimension

In a clinic, what seems to matter most is to understand how a disease is affecting a patient's life now, today, so that appropriate action can be taken. Nearly all QoL measures are designed to measure that current impact. But having a skin disease can influence Major Life Changing Decisions (MLCD)⁴⁹ and so the life impact can echo down the years, while chronic skin disease causes cumulative life course impairment.⁵⁰ The term "the Three Dimensions of QoL impact" (Now, Family and Long-term)⁵¹ was suggested to emphasise the importance of this temporal aspect of QoL (Fig 3): a template to record MLCDs⁵² has also been developed.

Insert Figure 3 here

Conclusion

This review describes a series of concepts developed over three decades while researching QoL in dermatology. Attention to some of these broader issues, in addition to fully validating new tools, may be of benefit to developers of novel QoL measures or other PROMs.

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Figures

Figure 1.

(A) Summary of steps in creation of a new quality of life measure.

(B) Framework and interconnectivity of concepts described, encompassing validation.

Figure 2.

The Rule of Tens to describe current severe psoriasis.³⁸

Figure 3

The Three Dimensions of QoL impact:⁵¹ Now, Family⁴⁰ and Long-term.

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