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15<sup>th</sup> September 2016

**Why quality of life measurement is important in dermatology clinical practice**

**An expert-based Opinion Statement by the EADV Task Force on Quality of Life**

Finlay AY, Salek MS, Abeni D, Tomás Aragonés L, van Cranenburgh OD, Evers AWM, Jemec G, Linder D, Manolache L, Marrón SE, Prinsen CAC, Susitaival P, Chernyshov P on behalf of the EADV Task Force on Quality of Life.

Running Head

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## **Key words**

Quality of Life, dermatology clinics, patient-reported outcomes, clinical assessment, decision-taking, clinical practice

## **Abstract**

The aim of this study was to describe the many ways in which quality of life (QoL) measurement may potentially be advantageous in routine clinical dermatology practice. Thirteen members of the EADV Task Force on Quality of Life, eight dermatologists, three health psychologists, one epidemiologist and one pharmacoepidemiologist, independently listed all of the ways they thought this may be advantageous. 108 different way of using QoL information in clinical practice were suggested (median per participant=8, range=4-15), and were classified into 20 descriptive groups. These were sorted into five categories: Inform clinical decisions, Clinician-patient communication, Awareness of skin disease burden, Informing the consultation and Clinical service administration. The wide range of potential benefits identified may encourage clinicians to use these measures but also highlights many areas requiring evidence to establish the true value of routine use of QoL measures.

## **Introduction**

The aim of this paper is to identify in what ways health-related quality of life (QoL) measurement may be of benefit in routine dermatology clinical practice. Since the first dermatology disease specific QoL measure publication<sup>1</sup> 30 years ago, the assessment of patients' QoL is now frequently included in dermatology research studies<sup>2</sup>. The measurement of QoL using validated instruments is recommended in dermatology therapy guidelines in many countries<sup>3,4,5</sup> and consequently many clinicians worldwide have become familiar with these measures. Anecdotally, some clinicians also use them in their routine clinical work but there is little published about such usage and a systematic review found limited evidence of impact<sup>6</sup>. Some advantages and disadvantages of routine use of QoL measures in dermatology clinics<sup>7,8,9,10</sup> and other specialties<sup>11,12,13</sup> have since been described.

The European Academy of Dermatology and Venereology (EADV) Task Force on QoL considers that there are several ways in which the measurement of QoL in clinical practice may benefit patients, support clinicians' decision taking and contribute to delivery of high standards of care, though the evidence for this is very limited. The aim of this Opinion Statement is to describe the many ways in which the use of QoL measures may be advantageous in clinical practice. This

Opinion Statement also aims to encourage clinicians to use QoL measures in practice and to be a source of reference. An additional aim is to identify aspects of the use of QoL measures in clinical practice for which more research is needed to establish their actual, evidence based, value.

## **Methods**

The Opinion Statement is confined to QoL measures, and does not address other components of Patient-Reported Outcomes (PROs), such as those recording symptoms, patient satisfaction or preference.

All members of the EADV Task Force on QoL, including dermatologists, psychologists and other health care professionals, were invited to contribute. A draft protocol was reviewed by all those who expressed interest in the study and changes were made. Each participant was asked to independently write a list of all the ways in which they considered QoL measurement is or could be useful in dermatology clinical practice. This was carried out before reviewing the literature, in order to encourage original thinking among participants and to capture what is actually practiced. All participants were asked to identify published articles of relevance that they were aware of in order to support this Opinion Statement.

All responses were examined independently by AYF and SS: each item was identified and classified. Consensus over classification was then reached during three detailed data definition meetings between AYF and SS.

## **Results**

All 36 members of the EADV Task Force on QoL were invited to contribute, 13 of these (36%) took part. Eight dermatologists, three health psychologists, one epidemiologist and one pharmacoepidemiologist, from 11 European countries, participated: six (46%) were female.

A total of 108 items were submitted by the 13 participants (median per participant= 8, range 4-15). These were grouped under 20 descriptive headings (Table 1) and assigned to five categories: Inform clinical decision, Clinician-patient communication, Impact on clinician and patient, Informing the consultation and Clinical service administration.

A summary of the key points identified by participants, with illustrative participant quotations (Appendix 1), is given under five main categories and 20 descriptive headings as follows:

### **1. Inform clinical decisions**

Aid treatment decision taking

Quality of life information may improve clinical decisions by making them more patient-centred. Quality of life scores can inform decisions relating to choosing appropriate therapy strategies, whether to discharge or admit. For example the Rule of Tens, that includes a QoL score, can be used to inform decisions over psoriasis therapy. (Quote 1)

#### Guideline use

Clinicians in many countries already use QoL measures routinely as recommended by national guidelines, to inform decisions especially relating to therapy of severe psoriasis. (Quote 2)

#### Shared decision taking

The use of QoL measures may encourage patients' involvement in shared decision-making. Patients' knowledge of non-medical aspects of their disease is complementary to the clinician's expertise in medical factors. (Quote 3)

#### Treatment goals

For many patients, particularly for those with chronic skin conditions, as well as for the clinician, improvement in QoL is the main treatment goal. Quality of life scores may guide therapy decisions, based on common treatment goals. They also inform the clinician when considering what potential risk will be tolerated by the patient. (Quote 4)

#### Treatment adjustment at follow-up

Quality of life scores can aid clinical decision-making such as dose adjustment or follow up therapy change, e.g. to reduce identified QoL impact more quickly. Treatment effects can be monitored over several follow-ups using QoL scores. (Quote 5)

#### Discharge decisions

QoL scores can influence the clinician to take more appropriate discharge decisions, for example if scores are high, delaying discharge or arranging additional support after discharge. (Quote 6)

## **2. Clinician-patient communication**

#### Clinician-patient relationship

Systematic assessment of patients' QoL in outpatients may enhance the clinician-patient relationship, especially if results are discussed during consultation. Their use demonstrates to the patient the clinician's awareness of the QoL impact experienced by the patient and indicates that the clinician cares about the patient and their preferred outcomes, not just the disease. (Quote 7)

## Clinician-patient enhanced dialogue

Reviewing the patient's responses to the QoL questionnaire items may provide structure to and direct the clinical discussion to areas of patient concern, encouraging an overlapping understanding of the disease between clinician and patient. Use of QoL measures may facilitate further discussion about treatment satisfaction, disease burden and treatment preferences. (Quote 8)

### **3. Awareness of skin diseases burden**

#### Impact on clinician

Use of QoL measures can make clinicians more aware of the patient's perspective, the burden experienced by the patient and their family<sup>14</sup> and that lesion severity is not necessarily correlated with impact on QoL. Clinicians may become more aware of the likely course of the impact of the condition on the patient and that clinically "cured" conditions may still impact QoL. At a glance the domains that are most affected are identified, so the discussion can be more focussed. Issues such as shame or depression may be revealed and clinicians may be more likely to counsel the patient and consider referral for psychological help. (Quote 9)

#### Impact on patient

Use of QoL measures may help verbalise a patient's feelings and give the patient greater insight and awareness of their disease and a sense of greater control over their disease and the consultation. It allows the patient to express their problems in a wider context than a traditional symptom based framework. One participant asserted that the use of QoL measures in itself may improve treatment outcome. Score changes over time help patients to be aware of changes in their disease impact and might make them more interested in their treatment outcome, leading to improved adherence. (Quote 10)

### **4. Informing the consultation: information aid for prognosis, monitoring, screening, adherence and referral**

#### Structured clinical assessment

Structured assessment of QoL should be a part of the overall assessment of disease severity, helping to limit observer variation.

#### Prediction outcomes/prognosis

An understanding of the current QoL burden on a patient may inform a clinician's predictions concerning patient therapy adherence, commitment to long term therapy and likely therapeutic outcome. (Quote 11)

#### Adherence/compliance

If by the use of QoL measures a patient is aware that their clinician understands their QoL burden, this may improve patient satisfaction and adherence/compliance with treatment. (Quote 12)

### Screening

Use of QoL measures can act as a screening process to reveal “hidden” physical, psychological and adjustment problems, to identify patients who may need referral to other specialists and to identify patients who may need additional support or care. (Quotes 13)

### Monitoring of disease course

Regular use of QoL measures can be used to assist monitoring the course of a condition or the effectiveness of therapy. Score change can be informative and alert the physician to the need for consideration of therapy change. Improvement in QoL may be the most important outcome of their care for many patients as well as for many clinicians. (Quotes 14)

### Education

Use of QoL measures, by revealing specific problems, may allow individualisation of educational input to the patient. Their use may also assist in the education of health care professionals, for example medical and nursing students, to help them understand the wider burden of skin disease. (Quote 15)

### Referral to other services

Systematic assessment of patients’ QoL, by revealing specific individual problems, may inform decisions concerning appropriate referral to other specialists or support services. (Quote 16)

## **5. Clinical service administration**

### Guideline use/development

The importance of understanding the QoL impact of skin disease on patients is recognized in many national guidelines, such as for severe psoriasis<sup>15</sup>, where QoL scores are part of the recommended criteria for therapy decisions. (Quote 17)

### Audit/Clinical audit

Quality of life measures can be used to audit service performance from the patient perspective. They can be used to audit changes to clinical service delivery or effectiveness of educational programmes as well as for comparison of outcomes of different service providers. (Quotes 18)

### Administration/policy



When prioritising patient referrals to a clinic, QoL scores could be used to identify patients needing an urgent appointment because of the high impact of the disease on their lives. Information from QoL measures may inform policy makers and inform decisions about which aspects of a service need to be developed. Quality of life scores can be used to identify patients needing expensive therapy and justify its use. The use of structured QoL measures may allow allied health personnel to act more independently of physicians. Quality of life measures may be used by patients as advocacy tools, quantifying and formalising their complaints. (Quotes 19)

One participant commented that patients are pleased that these issues are being tackled and that no patients had ever given any negative feedback on the use of QoL questionnaires. Another participant quoted that “only when you can measure something can you talk about it”, and that the focus in medicine towards management of chronic disease emphasises the important of measuring QoL in clinical practice.

## **Discussion**

Previous authors have addressed the potential benefits of routinely using QoL measures in a dermatology clinic<sup>8,9,7</sup>. Abeni et al<sup>8</sup> suggested that the (routine) measurement of QoL would help to identify patients experiencing major negative impact of their skin disease and may therefore need treatments that would not be the usual “first-line” treatments based on clinical severity alone, or other special support. Salek et al<sup>9</sup> suggested that improving QoL is becoming an explicit goal of healthcare in dermatology consultations. Van Cranenburgh et al<sup>7</sup> identified why HRQoL assessment is relevant for dermatologic practice and which patients would benefit most from routine HRQoL assessment. Aawar et al<sup>10</sup> suggested that using a patient’s QoL information can lead to optimized treatment decision-making, and be used to prioritize problems, facilitate communication, screen for potential risks, identify preferences and monitor response to treatment. Other potential benefits are in the training of new staff, in clinical audit and for clinical governance.

Cella et al<sup>12</sup> summarized the possible benefits of using patient reported outcomes in clinical care as: assisting clinical providers in managing their patients’ care<sup>16</sup>; enhancing the efficiency of clinical practice<sup>17,18</sup>; improving patient-provider communication<sup>17,19</sup>; identifying patient needs in a timely manner<sup>17,20</sup>; and facilitating patient-centered care<sup>17</sup>. All of these various points were mentioned independently by our study participants.

Although many dermatologists think they have good insight into the impact of disease on their patients, the concordance between clinician-reported measurements of disease burden and PRO measures appears to be poor<sup>21,22,23</sup>. Little information about QoL is normally elicited during routine dermatology outpatient consultations<sup>21</sup>, though dermatologists’ clinical decisions in outpatients concerning psoriasis management are related to the degree of

impact of psoriasis on the patient's QoL<sup>24</sup>. Salek et al<sup>25</sup> demonstrated that the routine use of QoL measures identified patients experiencing high impact on QoL. In 29% of consultations where a QoL measure was completed, the clinician used the QoL information and in 58% of these "use" consultations the QoL information influenced treatment decision taking, mainly in patients who were more severely affected than recognised by the clinician. Tabolli et al<sup>26</sup> found that using QoL assessment routinely in a dermatology unit was well accepted by patients and clinical staff, however the actual impact on clinical activities was limited. Finally, the use of QoL measures may contribute to giving patients "perceived control" over their skin condition, thereby improving the doctor-patient relationship<sup>27</sup>.

In dermatology and in other specialties, there is some evidence about possible advantages for routine use of a QoL measure. For example, routine use of a QoL measure in an oncology practice raised awareness amongst physicians of patient functioning and facilitated communication without prolonging the consultation<sup>13</sup>. There were many episodes of the QoL measure identifying issues that might not otherwise have been recognised, including depression, erectile dysfunction and therapy-induced fatigue. Moreover, a study to compare the use of three different QoL measures in a breast/prostate cancer clinic<sup>28</sup> unexpectedly demonstrated that participants from minority racial groups, with lower education and who had less computer usage were more likely to rate the use of a QoL measure favorably. This suggested that using patient reported outcome measures in clinical practice may be an effective approach for addressing the needs of these groups, a point not raised in our study. Furthermore, the routine use of QoL measures may act as an ongoing educational process for the clinician, who may gain a greater insight into the reality of living with skin disease. In exceptional cases having the level of QoL impairment documented could provide evidence of appropriate clinical decision taking should that ever be challenged.

In urticaria management, routine use of QoL measures may improve and standardize medical record keeping and care but also release time for the actual physician-patient interaction<sup>29</sup>. Evers et al<sup>30</sup> emphasized the advantages for personalized healthcare approaches. For example, QoL instruments enable the identification of patients who would most likely benefit from treatments. Only those patients at need for help are offered treatment and patients can be offered treatments specifically tailored to their adjustment problems. Insight is also gained into treatment priorities and patient motivation. In addition, screening of risk and resilience factors may provide clues on where and how to intervene in a specific patient.

Our study was not designed to document negative aspects of the use of QoL measures but it is important to recognise that there are potential issues. One barrier has been the perception of increased work burden for the patient and physician<sup>13,31</sup>, but there may be no overall increased work burden for providers if QoL measures are used<sup>13</sup>. It is important that QoL questionnaires are not just completed by but are discussed with patients. If a patient completes a questionnaire but nothing is apparently done with it, this reduces motivation to complete another in the future. However one study participant stated that

patients are very pleased when QoL measures are used and no patient had ever given negative feedback to them about their use.

It is likely that the use of computer-based assessment of QoL will become integrated into clinical practice: the use of such a tool designed for children has been successfully trialled<sup>32</sup>: its use was considered to have the potential to improve patient-physician communication. However, the implementation of a web-based system to collect patient reported outcomes including QoL encountered some logistical issues and time constraints<sup>33</sup>.

One practical aspect of the use of QoL measures in routine clinical practice not mentioned by the participants is the importance of clinicians to be able to interpret the scores, and also to have a basic understanding of the Minimal Clinically Important Difference (MCID) of scores. Validated descriptor score bands and cut-off scores may be helpful to clinicians<sup>34,35,36</sup>. There is great potential for such information and instant interpretation of scores to be given automatically to clinicians if QoL measures were to be used online, both for direct clinical purposes and for screening<sup>30</sup>.

Another aspect is the potential in paediatric consultations of enhancing the communication between children and their parents or carers. By comparing the results of a QoL measure completed by a child with the assumption of the parent, the parent may gain a greater understanding of the child's perspective<sup>37</sup>.

There are few publications that either describe or suggest the use of QoL measures in routine clinical practice, or describe the use of QoL information to support clinical decision-making in routine practice. Given that there are many anecdotal reports of such use, this is an area that requires further documentation, validation and dissemination of good practice. Muller et al<sup>38</sup> state that QoL measurement offers major benefits for the treatment of skin diseases and that first experiences of implementing QoL measures into practice have been positive. Although we did not carry out a systematic review regarding advantages and disadvantages of integrating QoL measurements in routine clinical practice across all medical specialties, it is likely that the advantages and disadvantages identified in this Opinion Statement would equally apply in other medical specialties. However, as the experience of the contributors was mainly in dermatology, caution should be taken in the application of the results to other fields of medicine.

In conclusion, the 20 different potential aspects of benefit of routine use of QoL measures in routine practice that have been suggested by the study participants provide clear encouragement for the wider gaining of experience of their use. However, there is virtually no evidence to back up most of these suggestions, highlighting a wide array of research questions that need to be prospectively addressed.

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## **Table**

Table 1. Description of the 20 items suggested by the 13 participants

## **Appendix 1**

Quotes from participants illustrating each concept

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Table 1. The 20 descriptors, given in five categories, of the 108 items mentioned by the 13 participants (median number of items mentioned per participant = 8, range 4-15).

	Number times items mentioned	Number of clinicians mentioning <u>these items</u>
<b><u>1. INFORM CLINICAL DECISIONS</u></b>		
<i>Aid treatment decision taking</i>	8	8
<i>Guideline use</i>	1	1
<i>Shared decision taking</i>	4	3
<i>Treatment goals</i>	2	1
<i>Treatment adjustment at follow-up</i>	3	3
<i>Discharge decisions</i>	2	2
<b><u>2. CLINICIAN-PATIENT COMMUNICATION</u></b>		
<i>Clinician-Patient relationship</i>	4	3
<i>Clinician-Patient enhanced dialogue</i>	<u>11</u>	7
<b><u>3. AWARENESS OF SKIN DISEASE BURDEN: IMPACT ON CLINICIAN AND ON PATIENT</u></b>		
<i>Impact on clinician</i>	<u>20</u>	8
<i>Impact on patient</i>	<u>6</u>	4
<b><u>4. INFORMING THE CONSULTATION</u></b>		
<i>Structured clinical assessment</i>	<u>1</u>	<u>1</u>
<i>Prediction outcomes/prognosis</i>	4	3
<i>Adherence/Compliance</i>	3	3
<i>Screening</i>	7	5
<i>Monitoring</i>	<u>10</u>	<u>9</u>
<i>Education</i>	5	4
<i>Referral to other services</i>	4	4
<b><u>5. CLINICAL SERVICE ADMINISTRATION</u></b>		
<i>Guideline development</i>	1	1
<i>Audit/Clinical Audit</i>	6	4
<i>Administration/policy</i>	6	4



## **Appendix 1**

Quotes from participants illustrating each concept

### **Guide clinical decisions**

Quote 1: Aid treatment decision taking.

*"... QoL measurement may ... help dermatologists in making more informed, and thus – hopefully - better, decisions about the treatment/management of their patient's diseases."*

Quote 2: Guideline use

*"Use as part of guideline protocols, e.g. NICE or BAD guidelines."*

Quote 3: Shared decision taking

*"By assessing health-related QOL in clinical practice and discussing the results with the patient, patients with chronic skin diseases are directly involved in the care process. This in turn contributes to shared-decision making and higher patient satisfaction."*

Quote 4: Treatment goals

*"....necessary in determining the treatment - what are the treatment goals?"*

Quote 5: Treatment adjustment at follow-up

*"....adjusted my therapy in order to reduce sooner the impact (sometimes, the therapy could be different than we had thought before measuring the QoL)"*

Quote 6: Discharge decisions

*"Use to support clinical decision taking (discharge or follow-up)"*

### **Clinician-patient communication**

Quote 7: Clinician-patient relationship

*"It's a way of showing we care, that we are interested in the person, as well as the skin condition."*

Quote 8: Clinician-patient enhanced dialogue

*"Insight in HRQoL problems creates an opportunity to communicate in an empathic and responsive way, thereby supporting patients in coping with their problems more effectively. .... may be helpful in engaging patients in a discussion on treatment preferences to allow mutual- or shared decision making."*

### **Awareness of skin diseases burden**

Quote 9: Impact on clinician

*"At a glance we know which domains are most affected (in this way we can focus on the issues that are affecting the patient most) .... Great way of doing psychodermatology in your everyday practice."*

Quote 10: Impact on patient

*"By filling out a HRQoL questionnaire .... patients may gain more insight into the impact of the skin disease on their own physical, psychological and social functioning and well-being. .... this insight will increase patients' self-awareness, for instance awareness of specific psychological problems and of specific health care needs. Such awareness, and the acknowledgement of needs by the dermatologist, may further empower patients to share and discuss their problems with significant others, such as a partner, relatives and friends."*

**Information aid for prognosis, monitoring, screening, adherence and referral**

Quote 11: Prediction outcomes/prognosis

*"Made a prediction about the future cooperation and patient's adherence and commitment for a long-term treatment."*

Quote 12: Adherence/compliance

*"The doctor's perception of the patient's quality of life may influence patient satisfaction with care and adherence to treatment."*

Quotes 13: Screening

*"Use to identify patients who may need psychological support or referral to nurse specialists."*

*"Furthermore, patients' needs for additional care, as a supplement to regular dermatological care, can be identified and addressed."*

Quotes 14: Monitoring of disease course

*"...to monitor treatment over time, modify treatment if needed and to determine treatment effectiveness."*

*"Monitoring the course of a condition, or evaluating the effectiveness of treatment, from the point of view of the patient is different than from the point of view of the doctor."*

*"An improvement in HRQoL, which is a main treatment goal for many patients, can be monitored, and may indicate treatment effectiveness."*

Quote 15: Education

*"Individualization of the educational part of consultation according to patients need."*

Quote 16: Referral to other services

*"To define patients who need consultations of specialists other than dermatologists (psychologists, psychiatrists etc)."*

## **Clinical service administration**

### **Quote 17: Guideline use/development**

*"Forming of disease-specific recommendations that may include peculiarities of different age groups, gender differences and correlations with .... patients' outcome measures."*

### **Quotes 18: Audit/Clinical audit**

*"Use to assess changes in way clinical service is provided for patients, (e.g, introduction of nurse-led clinics)."*

*"to track .... the performance of health care delivery organizations: to evaluate a clinic's quality of care over time, to compare the quality of care across clinics."*

### **Quotes 19: Administration/policy**

*"Use to identify patients who have been referred who need to be seen urgently."*

*"By providing a self-reported significant outcome measure it allows allied health personnel to act more independently of physicians, e.g. in nurse-led clinics."*