FRANCESCA SAMPOGNA

QUALITY OF LIFE AND SEVERITY ASSESSMENT BY PROVIDER AND PATIENT IN ORAL AND SKIN CONDITIONS
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QUALITY OF LIFE AND SEVERITY ASSESSMENT BY PROVIDER AND PATIENT IN ORAL AND SKIN CONDITIONS

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# TABLE OF CONTENTS

PREFACE ........................................................................................................ 9
ABSTRACT ....................................................................................................... 11
INTRODUCTION ............................................................................................. 13
    Patient and provider .................................................................................. 13
    Health-related quality of life ...................................................................... 15
    The severity of a disease ......................................................................... 15
    Oral and skin conditions ......................................................................... 16
    The evaluation of quality of life and severity by the provider
    and the patient self .................................................................................. 17
AIMS OF THE STUDY ..................................................................................... 18
MATERIALS AND METHODS .......................................................................... 20
    Population .................................................................................................. 20
        1. Paper I: skin diseases ..................................................................... 20
        2. Papers II and III: oral diseases ...................................................... 21
        3. Paper IV: oral mucosal diseases .................................................... 21
    Materials .................................................................................................... 22
        Demographics ....................................................................................... 22
        Clinical evaluation ............................................................................... 22
        Questionnaires ..................................................................................... 22
        Quality of life in dermatology : the Skindex-29 (Paper I) ............... 22
        Depression or anxiety: the General Health Questionnaire
        (GHQ-12) (Paper I, IV) ...................................................................... 23
This thesis is based on the following papers, referred to below by Roman numerals:


Paper I is reprinted with the permission of the British Journal of Dermatology, paper II with the permission of Community Dental Health, and paper III with the permission of the European Journal of Oral Sciences.
ABSTRACT

A good communication between patient and provider has the aim to understand the patient’s problems, to establish and maintain a caring relation, and to inform about disease. The quality of communication may have an influence on different important aspects, such as satisfaction and adherence to treatment.

In this thesis, the overarching aim was to evaluate the effects of the communication between patient and provider, by comparing their evaluation of either the health-related quality of life of patients, or the severity of the disease.

It was chosen to focus on oral and dermatological conditions, since skin and teeth are some of the most important components of the appearance of a person, and conditions which affect them can have deep psychosocial implications on patients’ life.

Paper I concerns skin conditions. Dermatologists’ opinions on skin health-related quality of life and psychological problems in patients were compared to the patients’ reports.

Papers II and III concern oral conditions. The evaluation of oral health-related quality of life problems in patients by the caregivers was compared to the evaluation given by patients.

In Paper IV, about oral mucosal conditions, the comparison was made between the evaluation of the severity of the disease by patients and providers.

Paper I: as regards quality of life, physicians tended to overestimate impairment in several conditions, particularly in alopecia. In many diagnostic categories, an underestimation of the frequency of depression and anxiety by dermatologists was observed.
Paper II and III: the correlation between patients’ and caregivers’ evaluation of oral health-related quality of life was low. In general, caregivers tended to overestimate the quality of life impairment of their patients, particularly for women, for elderly people, and for patients with a low number of teeth. The difference between patient and caregiver evaluation did not depend on the professional status of the caregiver (dentist or hygienist), nor on the clinics.

Paper IV: in oral mucosal conditions, the agreement between patients’ and providers’ evaluation of severity was very low. Physicians tended to underestimate severity more in older than in younger patients, and in patients with a higher quality of life impairment compared to the others. The underestimation by the physician was also positively associated to psychological problems and the presence of alexithymia.

This thesis showed a low agreement between patient and provider in the evaluation of quality of life and psychological problems of patients, and of the disease severity, both in dental and dermatological conditions. The discrepancies were both in the direction of an underestimation and an overestimation by the caregiver.
INTRODUCTION

Patient and provider

In clinical practice, an important relationship is established between two people: the patient and the provider. Each of them has a peculiar role. The patient is a person who has concerns about her/his health. The provider is a healthcare professional who has a contact with a patient, while that patient is seeking healthcare. They both have expectations, the patient mainly concerning recovering, the provider concerning, for example, how much the patient will follow her/his indications.

The patient and the provider meet at the clinical consultation, bringing their own characteristics (age, gender, education, etc.), personality, and experiences (Fig. 1). When they meet, they give each other some information. The patient informs the provider about her/his own health, and the provider informs the patient about the disease, its characteristics, symptoms, consequences and treatments. At the same time, deeper messages pass on between the two people. In a more or less conscious way, they also inform each other about feelings, emotions, and expectations. They communicate at different levels, and they build a relationship.

There are several reasons why this communication, and consequently the relationship, may be good or bad. It is not the aim of this thesis to evaluate them. However, it is important to remark that communication may have three tasks: to understand the patient’s problems, to establish and maintain a caring relation, and to inform about disease (1), and that the quality of communication may have an influence on different important aspects, such as satisfaction and adherence to treatment.
As a consequence of the consultation, the provider will have an insight of the health status and the wellbeing of the patient, which may or may not correspond to the reality of the patient. These perceptions can be described and compared using outcome measures, such as the severity of the disease, or the health-related quality of life of the patient.

In the present thesis, I will focus on the outcomes of the relationship between patient and provider, and in particular on the evaluation of the health-related quality of life and of the psychological status of the patient, and on the assessment of the disease severity, from the point of view of the patient and of the provider.

Figure 1. Schematic representation of the patient-provider relation
Health-related quality of life

In recent years, the concept of health-related quality of life has become an essential public health focus. This concept has its roots in the revolutionary concept of health given in 1946 by the World Health Organization: “a state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity”. The way to a new perspective on clinical care was open. The patient had to be considered as a whole, as body and mind, and her/his health did not depend only on the healing of her/his disease.

In the last decades, there has been a shift from a disease-centred, biomedical approach, to a “patient-centred” approach, which emphasizes the need to take into account the patients’ perceptions of the disease, their individual needs and preferences, and their emotional status (2, 3).

Although there is no universal definition of health-related quality of life, there is growing consensus that it is a multidimensional concept, including physical health, psychological state, and social relationships. Nowadays, in clinical practice, the issue of health-related quality of life is increasingly being regarded as an important component of the burden of disease suffered by the individual patients, and therefore as a relevant aspect of a comprehensive clinical assessment.

Providers must take into account the overall burden of the disease when choosing treatments. In a larger perspective, decisions on what research or treatments to invest the most in should be closely related to their effect on patients’ quality of life.

The severity of a disease

The definition of the severity of a disease is not straightforward. For many diseases, specific and complex criteria have been established.

For example, in some dermatological diseases, such as psoriasis, the assessment of severity includes the surface area involved, the desquamation, the erythema and the induration of the lesions. To define the severity of a periodontal condition, many characteristics have to be considered, such as the infectious and inflammatory status of the periodontal tissue, and the condition of the alveolar bone. Sometimes the final measure of the severity is a number, as for example the Psoriasis Area and Severity Index (PASI) (4). It is a way of summarize different characteristics, and can be useful in clinical studies to evaluate the clinical efficacy of a treatment. It is intended to be an “objective” measure.
of severity. However, it is a measure that considers the disease, but not the person who experiences it.

Severity can also be measured subjectively, both by the provider and the patient. This is what summary measures such as the Physician Global Assessment (PGA) and the Patient Global Assessment (PtGA) of severity are intended to do. The provider and the patient self are asked to evaluate the severity of the disease on a five-point scale, from “very mild” to “very severe”. The question is what severity is from the point of view of the provider and of the patient. The patient probably includes the general wellbeing into her/his definition.

The provider should be able to evaluate the disease not only from a clinical point of view, but also from the point of view of the patient.

**Oral and skin conditions**
The choice in this thesis to compare patient’s and provider’s evaluations of quality of life and severity in oral and skin conditions depends on the peculiar characteristics that these conditions share. Skin and teeth are some of the most important components of the appearance of a person, and conditions which affect them can have deep psychosocial implications on patients’ life.

Oral conditions can have a strong impact on the quality of life of patients, both from a physical and a psychosocial point of view (5, 6). Also dermatological diseases are known to have a strong impact on the quality of life of patients (7)—especially those associated with stigmatization (8)—and it is now widely documented that psychiatric disorders are common among patients with skin problems, with a substantially higher prevalence than in the general population (9, 10).

Thus, these are conditions where a patient-centred approach is particularly needed. In fact, it has been shown that clinical evaluation alone is not sufficient for a comprehensive assessment of the burden of such diseases on patients. The issues of health-related quality of life and psychological distress are increasingly regarded as important components of the burden of disease suffered by individual patients, and therefore as relevant aspects of a comprehensive clinical assessment.

In the field of dentistry, the concept of oral health-related quality of life (OHRQOL) captures the aim of this new perspective on health (11). In order to have information on the patient’s perception of his/her disease, many specific patient-centred measures have been and are cur-
rently used to assess the psychosocial impact of oral diseases on patients and its consequences on their quality of life (12-15).

Several instruments have been created to evaluate the quality of life of patients with dermatological diseases (16-19). These instruments may help providers to depict the burden the disease has on the patient, giving information on topics that cannot usually be discussed during a clinical examination, for example because of lack of time.

The evaluation of quality of life and severity by the provider and the patient self

It has been shown that clinicians’ ratings of oral health often do not correspond to patient self-ratings (20). Also in dermatology discrepancies exist between patients and physicians assessment of patients’ quality of life (21, 22). Also, research data suggest that the detection of psychiatric disorders by dermatologists is not completely satisfactory (23), and there is reason to suspect that this holds even more for dentists with the possible exception of dental phobia.

The individual perception of health by the patient is correlated with his/her quality of life. It is important for clinicians to be aware of the problems associated with quality of life, in order to provide ratings of the patients’ health more similar to those given by the subjects (24).

In fact, the dentist’s positive attitudes and communicative skills, and thus understanding patients, are closely related to patients’ satisfaction (25) and outcome of care (26). Also, discrepancies between patients’ and dermatologists’ opinions about severity and impact of disease are associated with lower satisfaction with care (27).
AIMS OF THE STUDY

This thesis has the following aims:

In dermatological conditions:
- to explore if dermatologists’ opinions about health-related quality of life and prevalence of minor non-psychotic psychiatric disorders in several dermatological conditions correspond to actual data from a large research project conducted in the same time dermatological institution some months before (paper I);
- to investigate whether in some dermatological conditions there is a tendency by dermatologists to under- or overestimate the impact of skin diseases on patients (paper I).

In oral conditions:
- to measure the agreement between patients and their caregivers on the patients’ health-related quality of life (paper II);
- to investigate the possible determinants of low concordance between patients’ and caregivers’ evaluation of the oral health-related quality of life, by analyzing data using multilevel analysis. In the analysis different patients’ demographic and clinical variables, the financial system, and the role of the different caregivers and clinics were considered (paper III).

In oral mucosal conditions:
- to compare the evaluation of the severity of different oral mucosal diseases by providers and by the patients themselves. The underlying hypothesis was that, even in the severity assessment of his/her
own disease, it is plausible and understandable that a patient does not provide a simple clinical evaluation, but includes subjective aspects, which contribute to the burden of a disease. This would lead to different results compared to the providers. In particular, we investigated if psychological problems of patients, such as depression, anxiety, and alexithymia, could be associated to a different perception of the disease severity in providers and patients (paper IV).
MATERIALS AND METHODS

Population
Six different populations were used in this thesis. One included patients with dermatological diseases, the second with oral conditions, and the third with oral mucosal conditions. The remaining three populations were the dentists and dermatologists involved.

1. Paper I: skin diseases
The study population was constituted by patients aged 18 years or more attending the outpatient clinics of dermatology and dermatological surgery of the IDI-IRCCS dermatological hospital located in Rome, Italy. Data were collected between mid-June and mid-July 1999 on predetermined days (9). In total, 4268 questionnaires were given at admission, and of these 3125 were returned. Of the returned questionnaires, 267 were blank, leaving a total of 2858 questionnaires for the analyses and a response rate of 67%. In order to have only complete questionnaires, another 279 subjects were excluded. The analysis was thus carried out on 2579 patients, who completed the GHQ-12, and on 2242 patients, who completed the Skindex-29.

Outpatients referred to the dermatological hospital presented a wide range of diagnoses: acne, alopecia, atopic dermatitis, bacterial and fungal infections, balanitis, benign skin neoplasms, changes in pigmentation, connective tissue diseases, contact dermatitis, insect bites, keratosis, lichen planus, nail diseases, parasitosis, psoriasis, seborrhoeic dermatitis, skin tumours, urticaria, vitiligo, warts, nevi.
All dermatologists of the outpatient clinics were involved. Forty-six (82%) out of 56 dermatologists who were contacted agreed to participate. Among them, 72% were men, and 65% were aged between 35 and 49 years.

2. Papers II and III: oral diseases
Data on oral diseases were collected in Sweden, in the region of Värmland, from June to December 2004, in the framework of a large Swedish study (28). The study population consisted of patients going to their dental caregiver, aged 19 years or more, able to write and speak Swedish, and having at least two previous visits with the caregiver. Four clinics were randomly selected, three in the largest city of Värmland, and one in a small town, in order to counterbalance demographic characteristics. Patients were evaluated by one of 27 caregivers (15 dentists and 12 hygienists), and each caregiver had to evaluate 20 patients. Data were collected for 485 patients, with a response rate of 81%. All the hygienists were women, and among dentists 33% were men.

3. Paper IV: oral mucosal diseases
The study population consisted of patients referred to the Oral Health Care Unit of the IDI-IRCCS dermatological hospital, located in Rome, Italy, from April 2005 to November 2006, and from February to July 2009. Inclusion criteria were: diagnosis of an oral mucosal condition, age ≥ 18 years, ability of understanding and reading Italian, absence of cutaneous involvement (e.g., cutaneous pemphigus with mucosal involvement was excluded).

For the purpose of our study, oral conditions were then grouped by a senior dermatologist into eight categories: 1. Recurrent aphthous stomatitis (RAS); 2. Burning mouth syndrome (BMS); 3. Non malignant lesions, including fibroma, papiloma, leukoplakia, and epithelial hyperplasia; 4. Bacterial and fungal diseases, including candidiasis and scialoadenitis; 5. Morphology and color changes of tongue, including geographic and hairy tongue; 6. Oral lichen planus (OLP); 7. Oral pemphigus. Diseases that were not frequent enough to constitute a group (such as angular cheilitis or xerostomia) were included in the “other” group. Three dermatologists participated in the study, two women and a man.
Materials
Collection of data was based on questions about demographics, on a clinical evaluation by the physician, and on self-administered questionnaires concerning quality of life and psychological status of patients.

Demographics
For each study population, demographic data were collected concerning gender, age, marital status, and educational level (primary school, secondary school, or college/university). In dental conditions, information on the financial system to which each patient belonged, either fee-for-service or contract care, was also collected. In fact, in an evaluation study on these systems recently conducted (28), it has been found that there were differences in patients’ health, with respondents in contract care having better oral health-related quality of life than those in fee-for-service care.

Clinical evaluation
In all the studies reported, the caregivers assessed the patients’ either dermatological or oral condition on the basis of the visit and the patient records. In the study reported in Papers II and III, caregivers were also requested to classify the patient’s oral status, on the basis of the number of bleeding gums, the caries status and previous fillings, and the number of remaining teeth. Patients were classified as healthy, with general gingivitis, moderate, severe and complicated peridontitis. Moreover, caregivers had to assess the patient’s risk level, according to a set scheme, based on four categories: general (G), technical (T), caries (C), and periodontal risk (P) (28). Each risk category is assessed from 0 (no risk) to 3 (severe risk), and the risk group classification is calculated as G+2*T+C+P. There are a total of 16 risk groups (0-15).

Questionnaires
Quality of life in dermatology: the Skindex-29 (Paper I)
Skindex-29 is a reliable and valid instrument that has been specifically designed for measuring health-related quality of life in dermatological patients (29). It is a self-administered questionnaire, constituted by three scales assessing areas considered essential in any instrument purported to assess quality of life: burden of symptoms, social functioning and emotional state. In this study, we used the Italian version of the
questionnaire (30). Patients answered the 29 questions referring to the previous 4-week period, on a five-point scale, from ‘never’ to ‘all the time’. The total score of each scale was given by the sum of the scores given to each question.

Patients with a total score <5 were classified as having an excellent quality of life. In a previous study (9), clinically severe psoriatic patients had a Skindex-29 total mean score of about 37. Hence, patients with a Skindex-29 score $\geq 35$ were classified as having a very poor quality of life. Intermediate scores were then categorised using cutoffs of 15 and 25.

Depression or anxiety: the General Health Questionnaire (GHQ-12) (Paper I, IV)
The GHQ is a self-administered questionnaire designed to measure psychological distress and to detect current non-psychotic psychiatric disorders, such as depression and anxiety (31). Questions refer to the most recent weeks. The 12-item Italian version was used (32). The reliability and validity of this instrument has been consistently demonstrated, recently also in dermatological patients (33).

Scores are given on a four-point linear scale and higher scores on the GHQ-12 indicate a higher level of psychological distress. The lowest cutpoint was set below the prevalence of depressive and anxiety disorders that has usually been observed in general population studies (about 10%). We classified prevalence rates as ‘low’ ($<10\%$), ‘normal’ ($\geq 10<15\%$), ‘relatively high’ ($\geq 15<20\%$), ‘high’ ($\geq 20<30\%$), and ‘very high’ ($\geq 30\%$).

Oral health-related quality of life: Oral Health Impact Profile (OHIP-14) (Papers II, III, IV)
To measure oral quality of life, the short form of the OHIP measure, the OHIP-14, (34) was used for assessment both by the patient and by the caregiver. The Swedish version of this instrument has been recently validated (35).

The OHIP measure is one of the most developed available oral quality of life measures. It contains measures of physical, psychological and social abilities, general physical function, ability of speech and eating, symptoms of pain and discomfort, and appearance and social embarrassment.
The questionnaire was originally addressed to the patients. However, in this study the same questionnaire was administered to the caregivers, wording the questions in order to assess how caregivers thought each patient experienced his/her oral problems. For example, the question “How often have you had painful aching into your mouth?” was for the dentist transformed into “How often do you think your patient has had painful aching into his/her mouth?”.

Answers to the OHIP questions were given on a five-point scale: 0=“never”, 1=“hardly ever”, 2=“occasionally”, 3=“fairly often”, 4=“very often”. The total OHIP score was calculated summing the score of each question, and thus higher scores indicate worse quality of life impairment. When one or two answers were missing, the total score was calculated by replacing the missing answers with the mean value of the completed items, while for more than two answers missing, the total score was considered as missing.

**Alexithymia: 20-item Toronto Alexithymia Scale (TAS-20)** (Paper IV)

The TAS-20 questionnaire (36, 37) was used to evaluate alexithymia. It gives three subscale scores, measuring respectively the difficulty in identifying feelings, the difficulty in describing and communicating feelings, and the tendency to focus on the concrete details of external events rather than on feelings, fantasies, and other aspects of one’s own inner experience (“externally oriented thinking”). There is evidence of internal consistency, test-retest reliability and factorial validity for the Italian version of the TAS-20 (38).

The scores of each item were summed to give the total score. The classical cutoffs are: below 52, people are classified as non-alexithymic, between 52 and 60 as borderline alexithymic, and more than 60 as alexithymic.

**Disease Global Assessment**

In Paper IV, for each patient, an overall clinical severity evaluation of the disease was given by the provider and by the patient him/herself. The Physician Global Assessment (PGA) and the Patient Global Assessment (PtGA) were operationalized in the question “In your opinion, compared to other patients with the same condition, how severe is the disease of patient X?”, and “In your experience, how severe is your
disease?”, respectively. Answers were given on a 5-point scale: “very mild”, “mild”, “moderate”, “severe”, “very severe”.

Comparison between patients’ and caregivers’ evaluation
The main outcome of the papers included in this thesis was the comparison between the evaluation of either severity, quality of life, or psychological status of patients, by the caregiver and by the patient her/himself.

The different evaluations given by patients and caregivers are summarized in Table 1. In Paper I, the comparison concerned the opinion of dermatologists about health-related quality of life and prevalence of depressive and anxiety disorders in patients with different dermatological conditions, and the actual scores obtained by the patients, using specific instruments (the Skindex-29 and the GHQ-12). The questions were: “According to your experience, and in general in your opinion, how would you rate the quality of life of patients with [diagnostic category Y]?”, with possible answers: excellent (1), good (2), fair (3), poor (4), very poor (5); and “According to your experience, and in general in your opinion, how frequent is a concurrent depressive or anxiety disorder in patients with [diagnostic category Y]?”, with possible answers: very infrequent (1), infrequent (2), somewhat frequent (3), quite frequent (4), very frequent (5).

In Paper II and III, the comparison was done between the evaluation of oral health-related quality of life, as measured by the patient using the OHIP-14, and by the caregiver using the same instruments, reworded for the caregiver.

In Paper IV, the PGA and the PtGA scores were compared.

Table 1. Compared outcomes in the four papers

<table>
<thead>
<tr>
<th>Paper I</th>
<th>Type of evaluation</th>
<th>Caregiver’s evaluation</th>
<th>Patient’s evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dermatological conditions</td>
<td>Quality of life</td>
<td>General opinion about quality of life of patients with a diagnosis X.</td>
<td>Skindex-29</td>
</tr>
<tr>
<td>Dermatological conditions</td>
<td>Psychological problems</td>
<td>General opinion about the presence of a concurrent depressive or anxiety disorder in patients with diagnosis X.</td>
<td>GHQ-12</td>
</tr>
<tr>
<td>Paper II, III</td>
<td>Oral health-related quality of life</td>
<td>OHIP-14</td>
<td>OHIP-14</td>
</tr>
<tr>
<td>Oral conditions</td>
<td></td>
<td>reworded for the caregiver</td>
<td></td>
</tr>
<tr>
<td>Paper IV</td>
<td>Oral mucosal conditions</td>
<td>Severity</td>
<td>PGA</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>PtGA</td>
</tr>
</tbody>
</table>
Statistical methods

In study I, the categories of dermatologists’ opinions about health-related quality of life and prevalence of psychiatric morbidity were plotted against the categories of quality of life and psychiatric morbidity actually observed. The relationship between physician evaluations and observed data was measured by the Spearman correlation coefficient. The sign test was used to test for systematic differences between dermatologists’ opinion and actual data.

In study II, differences in quality of life evaluation were analyzed comparing the OHIP median scores and its single item scores in patients and providers, using the non-parametric Wilcoxon test for paired data, and the non-parametric Mann Whitney test for independent data. Cohen’s kappa was calculated to measure the agreement between the evaluations of patients and caregivers. A factor-analysis of the OHIP-14 was then performed, to see whether there were any meaningful underlying dimensions, and to investigate whether concordance rates were different for possible different aspects of quality of life. Spearman correlation coefficient was calculated between the OHIP-14 scores and the risk assessment, and the OHIP-14 scores and the number of caries/fillings. In order to study the internal consistency (i.e., to test whether items were sufficiently interrelated to justify their combination in an index) of the OHIP-14 both in patients’ and in caregivers’ questionnaires, Cronbach’s alpha was calculated.

In study III, multilevel analysis was used to assess the amount of variability (variance) due to the patients (level 1), the caregivers (level 2), and the clinics (level 3) in the difference between the patients’ and the caregivers’ evaluation of OHRQoL. The outcome variable was the difference between the caregiver OHIP score and the patient OHIP score. In this investigation, we tested eight models, using the OHIP difference as the dependent variable. In each model, the variance for the fixed effect (i.e. the levels) and the random effects (i.e. the intercept and other variables) was estimated. The first model was a null model, containing only the intercept. Then the variable “finance system” was included in the model. In the third model we added gender, age and education of the patients, and in the fourth model we added the number of teeth. Instead of the number of teeth, in model 5 the variable “periodontal status” was introduced, in model 6 “number of teeth with enamel caries lesions”, in model 7 “number of teeth with dentine caries lesions”, and
in model 8 “number of fillings” (i.e. the total number of surfaces filled). The likelihood of each model was compared with a previous model having the same variables minus one or more. The difference between the two models was tested using the chi-square test of the -2log likelihood difference. To test if the discrepancies between patients’ and caregivers’ evaluation might be different for different clinics, a third level (i.e. clinics) was added to the multilevel model. The same models were tested using linear regression (ordinary least squares, OLS), in order to compare the results with those of the multilevel analysis.

In study IV, Cohen’s kappa was calculated to measure the agreement between the evaluations of severity by patients and by physicians. In order to compare PGA and PtGA, we created 3 categories: “Agreement” = PtGA equal to PGA; “Physician overestimates” = PtGA lower than PGA; “Physician underestimates” = PtGA higher than PGA. After univariate analyses, two logistic regression models were tested in order to investigate the possible determinants of underestimation or overestimation of severity by the physicians. The dependent variables were, respectively, “physician underestimates” vs. “agreement + physician overestimates”; and “physician overestimates” vs. “agreement + physician underestimates”. As independent variables we included gender, age (continuous variable), OHIP-14 (continuous variable), GHQ-12 (case/non-case), TAS-20 (alexithymia/no alexithymia), and disease (categorical variable).
RESULTS

Paper I

Aims
To explore to which degree dermatologists’ opinions about health-related quality of life and prevalence of depression/anxiety in several dermatological conditions corresponded to patients’ reports.

Results
Figure 2 and Figure 3 show the correlation between dermatologists’ opinions and survey data respectively on health-related quality of life and frequency of psychiatric morbidity. Each point represents a diagnostic category. Points laying on the diagonal represent the diagnostic categories for which there is complete agreement. Categories at a 1-point distance from the diagonal indicate fair agreement, though with moderate underestimation or overestimation by dermatologists. A distance of two or more points indicates substantial under- or over-estimation.

As regards quality of life (Fig.2), the correlation between dermatologists’ opinion and survey data was 0.30 (p=0.15). Physicians tended to strongly underestimate impairment in patients with bacterial infections and in patients without objective signs of skin disease. On the other hand, there was an overestimation of problems in several conditions, particularly in alopecia. There was a statistical trend toward overestimation by dermatologists of the impairment in patients’ quality of life (p=0.06). There was a wide range of dermatologists’ opinions (sd>1) over herpes zoster, parasitosis, and absence of skin disease, while a very tight agreement (sd≤0.6) was found over benign skin neoplasms, nevi, and urticaria.
As regards psychiatric morbidity (Fig.3), the correlation between dermatologists’ opinion and survey data was 0.25 (p=0.23). In many diagnostic categories, an underestimation of the frequency of depression and anxiety by dermatologists was observed. The greatest differences were observed in contact dermatitis, herpes zoster, insect bites and bacterial infections, where physicians classified psychiatric morbidity as infrequent, whereas prevalence rates above 30% were actually observed. This tendency to underestimate psychiatric morbidity by dermatologists was highly significant (p=0.001). We found a wide scattering of dermatologists’ opinions (sd>1) for balanitis, lichen planus, parasitosis, skin tumours, and absence of skin disease, whereas there was a very tight concordance (sd≤0.6) among dermatologists with regard to keratosis, bacterial infections, fungal infections, and benign skin neoplasms.

Correlations between dermatologists’ opinion and survey data did not substantially vary, when computed controlling for physicians’ gender or clinical experience.

Fig. 2 Comparison of dermatologists’ opinion about quality of life in different dermatological conditions and quality of life according to patients’ reports using the Skindex-29.
Paper II

Aims
To measure the agreement between patients and their caregivers in evaluating patients’ oral quality of life.

Results
Data were collected for 485 patients. The response rate was 81%. The study population consisted of 444 patients with complete data, due to internal non-response. Fifteen dentists and 12 hygienists participated, each being visited by 10 to 20 patients.

Median values (and range) of patients and caregivers OHIP-14 scores were 3 (0-25) and 9 (0-42), respectively. In general, caregivers tended to
give higher scores (indicating a worse quality of life) in the evaluation of oral health-related quality of life of their patients than the patients themselves. Thus, the correlation between patients’ and caregivers’ answers was low (Spearman’s rho=0.21).

Table 2 shows Cohen’s kappa for different cutoffs of the OHIP scores.

**Table 2.** Sensitivity analysis of agreement in the evaluation of oral health-related quality of life by patients and caregivers. Cohen’s kappa coefficient is calculated using 6 different cut-offs for OHIP-14 total scores.

<table>
<thead>
<tr>
<th>OHIP cutoffs</th>
<th>1 (0/1+)</th>
<th>3 (≤3/4+)</th>
<th>5 (≤5/6+)</th>
<th>9 (≤9/10+)</th>
<th>10 (≤10/11+)</th>
<th>14 (≤14/15+)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cohen’s kappa</td>
<td>0.15</td>
<td>0.10</td>
<td>0.10</td>
<td>0.13</td>
<td>0.14</td>
<td>0.14</td>
</tr>
</tbody>
</table>

Factor analysis on the patients’ OHIP-14 gave as a result two main dimensions, one mostly clinical (6 items), and the other psychosocial (8 items). We calculated Cohen’s Kappa for patients and caregivers separately for the two dimensions, but we obtained low values as well. In Table 3, the median OHIP scores observed for different levels of some independent variables are reported. In general, caregivers gave higher scores than their patients. This was true especially for older people, and patients with lower education. Also, when patients had complicated periodontitis, caregivers evaluated the quality of life of patients as significantly more impaired than did the patients themselves. The discrepancy was particularly high when the number of decays and fillings was high, and for a low number of teeth. The same result was obtained for the risk assessment: for higher risks the median values were 6 and 16 for patients and caregivers, respectively.

The correlation between the risk assessment score and OHIP-14 was 0.17 in patients’ and 0.48 in caregivers’ evaluation. The correlation between the summary caries- fillings/crowns score and the OHIP-14 was 0.06 in patients and 0.25 in caregivers.
Table 3. Median OHIP scores in patients and caregivers according to different variables.

<table>
<thead>
<tr>
<th></th>
<th>patients</th>
<th>caregivers</th>
<th>p-value*</th>
<th>p-value §</th>
</tr>
</thead>
<tbody>
<tr>
<td>overall</td>
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<td></td>
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<td>gender</td>
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<td></td>
</tr>
<tr>
<td>men</td>
<td>203</td>
<td>3</td>
<td>9</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>women</td>
<td>241</td>
<td>4</td>
<td>10</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>age (years)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>&lt;30</td>
<td>71</td>
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<td>4</td>
<td>0.225</td>
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<tr>
<td>30-39</td>
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<td>0.003</td>
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<tr>
<td>40-49</td>
<td>110</td>
<td>3</td>
<td>9</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>50-59</td>
<td>87</td>
<td>2</td>
<td>13</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>60+</td>
<td>54</td>
<td>3</td>
<td>14</td>
<td>&lt;0.001</td>
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<td></td>
</tr>
<tr>
<td>primary school</td>
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<td>3</td>
<td>8</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>college/university</td>
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<td>4</td>
<td>7</td>
<td>&lt;0.001</td>
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<td>periodontal condition</td>
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<td>healthy</td>
<td>330</td>
<td>3</td>
<td>7</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>general gingivitis</td>
<td>57</td>
<td>4</td>
<td>10</td>
<td>0.001</td>
</tr>
<tr>
<td>moderate periodontitis</td>
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<td>severe periodontitis</td>
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<td>complicated periodontitis</td>
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<td>3</td>
<td>17</td>
<td>0.109</td>
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<td>No. of teeth</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;26</td>
<td>72</td>
<td>3</td>
<td>14</td>
<td>&lt;0.001</td>
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<tr>
<td>≥26</td>
<td>371</td>
<td>3</td>
<td>7</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

* From Wilcoxon test for paired data: comparison between patients’ and caregivers’ score in each group.

§ From Mann Whitney test for independent data: comparison of the OHIP difference in each group compared to a reference group.
Table 3 (cont). Median OHIP scores in patients and caregivers according to different variables.

<table>
<thead>
<tr>
<th>No. caries lesions in enamel</th>
<th>patients</th>
<th>caregivers</th>
<th>p-value*</th>
<th>p-value ‡</th>
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</thead>
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<td>0</td>
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<tr>
<td>1-4</td>
<td>154</td>
<td>4</td>
<td>7</td>
<td>&lt;0.001</td>
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<td>5+</td>
<td>71</td>
<td>4</td>
<td>3</td>
<td>0.015</td>
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<td>No. caries lesions in dentine</td>
<td>0</td>
<td>183</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>1-2</td>
<td>137</td>
<td>3</td>
<td>7</td>
<td>&lt;0.001</td>
</tr>
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<td>3+</td>
<td>59</td>
<td>6</td>
<td>12</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>No. fillings/crowns</td>
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<td>120</td>
<td>3</td>
<td>5</td>
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<tr>
<td>9-16</td>
<td>206</td>
<td>4</td>
<td>8</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>17+</td>
<td>109</td>
<td>3</td>
<td>13</td>
<td>&lt;0.001</td>
</tr>
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<td>No. caries lesions</td>
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<td>3</td>
<td>6</td>
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<tr>
<td>fillings/crowns</td>
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<td>4</td>
<td>7</td>
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<td>20+</td>
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<td>3</td>
<td>11</td>
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<tr>
<td>risk classification</td>
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<td>3</td>
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<td>6-8</td>
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<tr>
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<td>90</td>
<td>6</td>
<td>16</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

* From Wilcoxon test for paired data: comparison between patients’ and caregivers’ score in each group.

‡ From Mann Whitney test for independent data: comparison of the OHIP difference in each group compared to a reference group.

Note: totals may vary because of missing data
Paper III

Aims
To use multilevel analysis on the same data as those used in Paper II, to investigate the possible determinants of the low concordance between patients’ and caregivers’ evaluation of quality of life, taking into account different patient variables, the financial system, and the role of the different caregivers and clinics.

Results
For the analyses of the present study, data were complete for 432 patients (89%), due to both missing patient and caregiver responses. The mean OHIP difference, i.e., the difference between the caregivers’ OHIP and the patients’ OHIP was 4.4 (SD=8.2).

Tables 4a and 4b summarize the eight models tested, using both multilevel analysis and OLS. As to multilevel analysis, the null model (i.e., model 1) showed a between-caregiver variance (16.2) in addition to a larger within-caregiver variance (52.4). This indicated a dependency in data, with an intra-class correlation coefficient of 0.24. When the finance variable was added (model 2) the model significantly improved. The OHIP difference was significantly higher in patients belonging to fee-for-service system than in those in the capitation system. The addition of patients’ age, gender, and education (model 3) significantly improved the model (p<0.001), and reduced the individual variance by 11% of the original total variance. Age and gender were significantly associated to the OHIP difference (i.e., a higher difference for older patients and for females), while the finance system was no longer significant. In model 4, in addition to age and gender, a lower number of teeth was associated with a larger OHIP difference. The likelihood of the model was significantly improved (p<0.025), however, the individual variance only slightly decreased compared to the previous model (from 44.8 to 44.1).

The introduction of either the periodontal status (model 5), or the number of teeth with caries in enamel (model 6), or the number of teeth with caries in dentine (model 7), or the number of teeth with fillings/crowns (model 8), did not significantly improve the model. Neither the individual, nor the between-caregiver variance varied significantly, compared to model 3. The caregiver variance was more or less the same in all models.
The inclusion of the professional category as an independent variable added no information to the models. A three-level model was attempted with clinic as a third level, yielding no clinic variance.

The OLS analysis on the same data gave some different results. The regression coefficient estimation was especially different for gender, with lower values in OLS than in multilevel, and in the finance system, with slightly higher values in the OLS models. The association of the OHIP difference with the number of teeth was no longer significant when using the OLS analysis (model 4).
Table 4a. Multilevel and linear regression estimates for models 1 to 4 of the difference between caregivers OHIP and patients OHIP. Regression coefficients and standard errors.

<table>
<thead>
<tr>
<th>Model</th>
<th>Fixed effects</th>
<th>Multilevel</th>
<th>OLS</th>
<th>Multilevel</th>
<th>OLS</th>
<th>Multilevel</th>
<th>OLS</th>
<th>Multilevel</th>
<th>OLS</th>
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<td>1.71 (1.50)</td>
<td>3.51 (2.30)</td>
<td>2.52 (2.30)</td>
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<td>2.95 (4.70)</td>
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<td>Finance system</td>
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<td></td>
<td></td>
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<td></td>
<td>Capitation ref</td>
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<td>0.56 (0.60)</td>
<td>1.06 (0.70)</td>
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<td>0.60 (0.60)</td>
<td>0.35 (0.50)</td>
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<td>No. teeth with caries in enamel</td>
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<tr>
<td></td>
<td>No. teeth with caries in dentine</td>
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<td>No. fillings</td>
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</table>

Random effects:

<table>
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<tr>
<th>Level 1 (caregivers)</th>
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<tr>
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<td>16.1 (5.3)</td>
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<td>17.0 (5.4)</td>
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<td>17.0 (5.4)</td>
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<td>44.1 (3.1)</td>
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<td>2919.69</td>
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<td>5.71 &lt; 0.001</td>
<td>5.71 &lt; 0.001</td>
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Table 4b. Multilevel and linear regression estimates for models 5 to 8 of the difference between caregivers OHIP and patients OHIP. Regression coefficients and standard errors.

<table>
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<th>71</th>
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<td>-7.0 (2.44)</td>
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<td>Fee for service</td>
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<td>Men</td>
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<td>Women</td>
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<td>0.19 (0.33)</td>
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<tr>
<td>No. teeth with caries in enamel</td>
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<tr>
<td>No. teeth with caries in dentine</td>
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<td></td>
<td></td>
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<td>0.24 (0.18)</td>
<td>0.06 (0.20)</td>
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<td>No. fillings</td>
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<td>Level 1 (patient)</td>
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<td>4.8 (1.2)</td>
<td>4.8 (1.2)</td>
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<td>0.33 (0.36)</td>
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<tr>
<td>Adjusted R²</td>
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</tbody>
</table>
Aims
The aim of this study was to compare the evaluation of the severity of different oral mucosal diseases by providers and by the patients themselves. Severity was evaluated using the Physician Global Assessment score (PGA), and the Patient Global Assessment score (PtGA).

Results
Data on both PGA and PtGA were complete for 206 patients. Physicians scored patients’ clinical severity mostly as the central values, from “mild” to “severe”, while patients also attributed the “very mild” and “very severe” levels to their disease. Mean (sd) OHIP-14 score was 22 (13). Patients with probable depression or anxiety were 34% of the population, and 39% had alexithymia or “possible alexithymia”. In the three levels of severity (mild/very mild, moderate, severe/very severe), concordance of PtGA with PGA ranged from 45% to 49%, while 12% of patients evaluated as “mild/very mild” by physicians, were self-evaluated as “severe/very severe”. However, there were also 29% of patients, whose clinical severity was considered as “severe/very severe” by the physician, who evaluated their disease as “mild/very mild “.

Cohen’s kappa coefficient between PGA and PtGA, both recoded into 3 categories, was 0.18. Kappa was higher in patients with OHIP-14 scores ≥14 compared to OHIP-14 scores <14. No significant differences in concordance were observed in patients with and without depression or anxiety, nor with and without alexithymia. However, the analysis of the three PGA-PtGA categories showed a higher underestimation by physicians (or overestimation by patients) in the alexithymic group compared to the non-alexithymic, and in the GHQ cases group (i.e., patients with probable depression or anxiety) compared to the non-cases. Physicians’ underestimation concerned 43% of patients with alexithymia and only 25% of patients without (p<0.01), and 44% of GHQ cases vs 25% of non-cases (p<0.01).

A very high overestimation by the physicians was observed for pemphigus. No difference was observed between men and women, while underestimation of clinical severity by the physician increased with patient age and with OHIP-14 scores.
The results of the logistic regression models are shown in Table 5. In the first model (PGA<PtGA, table 5a), the only significant variable was OHIP-14 score, i.e. the severity was more underestimated by physicians for patients with a higher reported quality of life impairment. Physician overestimation (table 5b) was inversely associated with OHIP-14 score and TAS-20 score, and positively associated with oral pemphigus.

Table 5a and 5b. Results of the logistic regression models using as dependent variables “physician’s underestimates” and “physician’s overestimates”, respectively. Shaded areas indicate significant (or almost significant) OR.

<table>
<thead>
<tr>
<th>VARIABLE</th>
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<th>B-VALUE</th>
<th>P-VALUE</th>
<th>OR</th>
</tr>
</thead>
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<tr>
<td>Gender</td>
<td>women vs men</td>
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<td>0.38</td>
<td>0.71</td>
</tr>
<tr>
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</tr>
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<td>0.01</td>
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</tr>
<tr>
<td>GHQ-12</td>
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<td>0.45</td>
<td>1.39</td>
</tr>
<tr>
<td>TAS-20</td>
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<td>0.17</td>
<td>1.65</td>
</tr>
<tr>
<td>rAS</td>
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<td>0.69</td>
</tr>
<tr>
<td>Non malignant lesions</td>
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<td>0.45</td>
<td>0.55</td>
</tr>
<tr>
<td>BMS</td>
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<td>1.38</td>
</tr>
<tr>
<td>Bacterial and fungal</td>
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<td>0.54</td>
<td>0.33</td>
<td>1.72</td>
</tr>
<tr>
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<tr>
<td>OLP</td>
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<td>0.92</td>
</tr>
<tr>
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<td>0.18</td>
<td>1.99</td>
</tr>
<tr>
<td>Improvement of predicted cases</td>
<td></td>
<td>3.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Model Chi-square</td>
<td>26.3, 12 df; p=0.01</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Nagelkerke R Square</td>
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<td></td>
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<tr>
<td>VARIABLE</td>
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<td>P-VALUE</td>
<td>OR</td>
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<tr>
<td>--------------------------</td>
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<td>---------</td>
<td>---------</td>
<td>-----</td>
</tr>
<tr>
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<td>0.43</td>
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<tr>
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<td>0.93</td>
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<tr>
<td>TAS-20</td>
<td>alexithymia vs no alexithymia</td>
<td>-1.04</td>
<td>0.04</td>
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</tr>
<tr>
<td>RAS</td>
<td></td>
<td>-0.28</td>
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<td>0.08</td>
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<td>OLP</td>
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<td>0.68</td>
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<td>3.39</td>
<td>0.004</td>
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Improvement of predicted cases 2.5
Model Chi-square 38.2, 12 df, p=0.001
Nagelkerke R Square 0.29

OR = odds ratio; PGA = Physician Global Assessment; PtGA = Patient Global Assessment; OHP-14 = 14-item Oral Health Impact Profile; TAS-20 = 20-item Toronto Alexithymia Scale; GHQ-12 = 12-item General Health Questionnaire; RAS = Recurrent Aphthous Stomatitis; BMS = Burning Mouth Syndrome; OLP = Oral Lichen Planus
DISCUSSION

Methodological discussion

Design of the studies
All data in this thesis emanate from cross-sectional studies, in which patients and caregivers were asked to evaluate either quality of life or severity. However, there are some methodological differences among studies. In study I, the comparison was not done on the patients of the providers. The evaluation of quality of life and psychological problems by the patients was compared to a general opinion of the dermatologist on an average patient with a given condition.

On the other hand, studies II, III, and IV compared the evaluation by the caregiver on a specific patient with the self-evaluation by the same patient. In these studies, patients and caregivers were asked exactly the same questions – the OHIP-14 for papers II and III, and the PGA/PtGA for paper IV.

Statistical analysis
In paper III, beyond the usual statistical tests, data of study II were analysed using multilevel analysis. The aim was to investigate the possible determinants of the low concordance between patients’ and caregivers’ evaluation of oral health-related quality of life. In the analysis we took into account different patient demographic and clinical variables, the financial system, and the role of the different caregivers and clinics.

It has been shown that multilevel modelling is a useful method for many situations in dental research where data belonging to different levels are to be analysed (39, 40). The comparison of the coefficients obtained using multilevel analysis with those obtained by OLS confirmed
the importance of taking into account different levels. In fact, the re-
gression coefficient estimations were quite different in some respects.
The different results obtained using OLS models and multilevel analyses
are due to the fact that dependency among data is removed in the mul-
tilevel analysis. Of the OLS and multilevel models, the latter are more
credible, because the model is better specified. The results thus indicated
that the multilevel analysis should be used on level structured data.

**Factual discussion**

**Findings**

In this thesis, it was generally observed a low agreement between pa-
tients’ and providers’ evaluation of quality of life and severity in oral
and dermatological conditions. Figure 3 summarizes the main results,
showing that the agreement was reached in a range from 29% to 49%
of cases. The first two bars represent the percentage of dermatological
diseases. The bars concerning papers II and IV represent the percentages
of agreement between patient and caregiver, and underestimation/over-
estimation by the caregiver. In paper II, agreement was considered as an
OHIP difference between patient and caregiver from -2 to +2.

The underestimation by the caregiver was particularly high in recog-
nizing psychological problems in several dermatological conditions. On
the contrary, in dental conditions, the caregivers tended to overestimate
the quality of life impairment of patients.
Comparison with previous findings

Until now, few studies have been conducted on the comparison between patients’ and providers’ evaluation of quality of life in dermatological conditions. A study showed that dermatologists might underestimate the subjective impact of skin disease on quality of life in patients with relatively benign or quiescent disease, while they might overestimate the subjective impact of more malign or aggressive skin disease (22). Also in our study I, it was observed an overestimation of quality of life impairment in patients with skin tumours or connective tissue diseases, while non life-threatening conditions, such as dermatitis, were underestimated. Other investigations showed that dermatologists tended to underestimate the prevalence of psychiatric morbidity among their patients (23), and that the level of agreement between dermatologists and patients as to the presence of anxiety and depression was low (41).

Concerning oral conditions, some studies have been conducted in order to compare caregivers’ and patients’ evaluation of either oral health (20, 42), or quality of dental care (43-45). However, as far as we know, no specific studies on the evaluation of oral health-related quality of
life have been conducted. The results of the previous studies were discordant. Concerning oral health evaluation, Atchison et al (20) found that the dentists tended to rate a subject higher on this point than the subject rated him- or herself, while Palmqvist et al (42) observed that respondents tended to assign more positive self-rating than the dentist rating. There was also a low agreement between quality of dental care as perceived by the patient and as measured by the dentist (43, 45). In particular, in the assessment of the quality of dentures, there was close correspondence between dentists’ and patients’ appreciation when the dentures were poor, but little or no correspondence in the other cases.

As far as known, no specific studies have been conducted on this subject in patients with oral mucosal conditions.

**Determinants of concordance/discordance**

In paper III, it was observed that the variance due to patients was partly explained by their age (higher OHIP difference between patient and caregiver for elderly vs. young patients), gender (higher OHIP difference for women vs men), and number of teeth (higher OHIP difference for patients with fewer teeth). In other words, the oral health-related quality of life impact on patients’ was overestimated by caregivers particularly for women, for elderly people, and for patients with a low number of teeth. The difference between patient and caregiver evaluation did not depend on the professional status of the caregiver (dentist or hygienist), nor on the clinics.

In oral mucosal conditions (paper IV), we did not observe any significant difference in the physician-patient agreement as to gender of patients. However, in this study physicians tended to underestimate severity more in older than in younger patients, and in patients with a higher quality of life impairment compared to the others. The underestimation by the physician was also positively associated to psychological problems and the presence of alexithymia. The result concerning alexithymia was particularly interesting, because it is possible that the condition of alexithymia, which is often correlated to depression, led the patients to evaluate their disease as particularly severe compared to the clinical evaluation. Also, it is plausible that patients with alexithymia could be more reluctant or incapable in communicating subjective problems caused by the condition. However, this result was no longer significant in one of the regression models.
Possible reasons for the low agreement between patients and providers

*Skin conditions*

In study I, the provider evaluation consisted of a general opinion about patients’ quality of life and psychological distress in a given dermatological condition. The comparison of these data with actual data collected on patients showed large discrepancies. These discrepancies might at least in part descend from conceptual models of skin disease that are common among dermatologists. In fact, the dermatologists’ perception of their patients’ psychological well-being and health-related quality of life is influenced by their cultural models of illness. Perception is strongly influenced by the observer’s expectations and conceptual models. All human knowing processes are proactive, and hence anticipatory, in nature. There is a complex neural architecture that underlies expectancy operation (46), and many studies in neurophysiology and motor learning have shown that human brain activities involve powerful feedforward mechanisms that proactively influence patterns of perception (47). Hence, it is more difficult to grasp the presence of something when it is not envisaged nor expected as compared to when it is possibly anticipated in one’s mind.

An example of this may be the overestimation by the dermatologists of the impairment in patients’ quality of life in skin tumours and connective tissue diseases. This discrepancy might be related to a different understanding by physicians of the biological implications and the prognosis of the disease. Particularly in the initial stages of disease, the quality of life of patients with skin cancer may not be substantially impaired, in spite of the possible severe consequences of the disease. Even the emotional impact of the disease seems to be less than one might expect, given that low levels of psychiatric morbidity have been observed in patients with malignant skin tumours (9). However, the dermatologist, influenced by his/her professional knowledge about the disease, might be led to overestimate its emotional impact on patients. Analogous considerations might be made for connective tissue diseases.

Discrepancies between patient and provider were particularly evident in the evaluation of psychological problems. Only in patients affected by classical dermatological diseases such as psoriasis, vitiligo, alopecia, lichen planus, pruritus, acne, and urticaria, we observed a good concordance between dermatologists’ opinion about the frequency of depressive
or anxiety disorders and the actual data on the prevalence of psychiatric morbidity. On the other hand, there was a substantial underestimation by dermatologists of concurrent psychiatric morbidity in patients with contact dermatitis, herpes zoster infections, bacterial infections, insect bites, herpes simplex infections, warts, and nail diseases, as well as in individuals without objective clinical signs of skin disease. A possible explanation of this finding is that dermatologists resorted mainly to the clinical severity of the various skin conditions in order to form their opinion about the frequency of depressive or anxiety disorders in each condition.

It should be underlined that patients with relatively mild skin conditions are usually catered by their general practitioner, and that patients coming to the attention of dermatologists might be those psychologically more distressed, who put pressure on their general practitioner for being referred to a specialist. The relatively high prevalence rates of psychiatric disorders that can be observed in patients with skin conditions like contact dermatitis, herpes zoster infections, bacterial infections, insect bites, herpes simplex infections, warts, and nail diseases, may partly be the consequence of a selection bias, because anxiety and depression might have induced patients with relatively mild skin conditions to seek medical help from a dermatologist rather than from their general practitioner. The extreme case is represented by those patients who complain of skin symptoms in the absence of appreciable clinical signs. Such patients often suffer from a psychiatric disorder, and probably search medical help mainly as a consequence of anxiety, depression, or sometimes psychosis. However, it should be recognised that the situation that has been depicted by epidemiological studies is the one actually faced by dermatologists in their everyday clinical practice, where they usually see patients who went beyond the filter of non-specialist settings.

**Oral conditions**

In papers II and III, we observed that also in dental conditions the agreement between patients and caregivers was low, with a general tendency by the caregivers to overestimate the burden of the dental conditions on patients’ life. As showed in previous studies, it is clear that patients and dentists look at different criteria when judging oral health (43, 48). As in dermatological conditions, discrepancies might at least in part descend from different conceptual models of oral disease among caregivers. For example, a patient could consider his/her quality of life as
not significantly affected by a serious disease, because it does not cause troublesome symptoms. On the other side, a caregiver, influenced by his/her professional knowledge about that disease, might be led to overestimate its emotional impact on patients. Another hypothesis about the discrepancies in the two evaluations could be the different frame of reference of patients and caregivers. Patients live their lives as a whole, and thus give less importance to a single component of their well-being. A tooth problem might become a secondary problem for a person, even though it is objectively a severe condition.

The overestimation of poor quality of life was particularly striking when patients had more severe conditions, in complicated periodontitis and in patients with many decays and fillings. Caregivers may have answered according to their general opinion on the disease, without really empathising with patients. Thus, they usually considered that a high risk assessment score or a severe dental condition was associated with a low quality of life, while for the patients this was not always true.

**Oral mucosal conditions**

Dental caries and periodontal diseases have historically been considered the most important oral public health burdens. However, also oral mucosal lesions and oral cancer may have an important impact on patients’ health (49). For these conditions, in study IV, we compared the evaluation of severity between patient and caregiver. The underlying hypothesis was that, even in the severity assessment of his/her own disease, it is plausible and understandable that a patient does not provide a simple clinical evaluation, but includes subjective aspects, which contribute to the burden of a disease. The discrepancies we observed confirmed that patients and providers take into account different aspects in evaluating the severity of a disease.

**Communication patient-provider**

A possible explanation of the low correlation we observed in all studies could be a poor communication between patients and caregivers (26). The lack of a mutual understanding of patients and providers, due to a non-efficient communication, can lead to severe consequences, for example concerning the adherence to treatment. Dentists who communicate with patients have better results on the treatment of fearful adult dental patients (50).
The communicative behaviour of dentists is related to patients’ satisfaction with treatment outcome, also because it helps patients to reach a well-informed decision about the treatment (25). It can also influence the choice of treatment. In a study exploring which factors affected patients’ decisions to pursue either surgical or non-surgical periodontal treatment (51), it was observed that the more the patients trusted their provider and felt they had good rapport, the more likely they were to accept surgical periodontal treatment. It is very important for a caregiver to build a positive rapport and trust with the patient (52).

Also in dermatological diseases, it has been shown (27) that patients’ satisfaction was associated to the physician’s ability to show empathy for the patient’s condition. In fact, the lowest level of satisfaction was found among patients whose symptom-related quality of life was worse than the clinical severity rated by the dermatologist. Patients’ satisfaction is particularly important in health care, since it has been shown to be strictly correlated to adherence to treatment (53).

Limits of the studies
In study I, it has to be recognised that the assessment of dermatologists’ opinions has limitations, such as the use of only a single question and the reference to an “average patient” for diseases which can range widely in severity. However, the findings indicate that dermatologists have fairly accurate opinions about the negative impact of the various skin conditions on patients’ quality of life, while they believe that psychiatric disorders are significantly less frequent than they actually are in patients with relatively minor skin conditions.

A possible limitation of studies II-III could be the caregivers’ voluntary participation. It is possible that those who participated, on average, had a better perception of patients’ status than the non-participants. Lacking a comparison group this explanation cannot be excluded, although unlikely.

Some limitations are also present in the instrument that was used to measure oral health-related quality of life, the OHIP-14. For example, in our data the so called “floor effect” was particularly evident, i.e. many answers were zero (=no impact) or very low. In previous studies of edentulous patients (54, 55) it was observed that patients with poor oral health had low scores in the OHIP-14. The measure does not seem to be suitable for all dental conditions. For example, the shortened
version of the OHIP does not contain any item relating to chewing difficulties, which is a frequent problem in patients wearing removable dentures (56).

However, for the purposes of this study, the limitations of the OHIP-14 questionnaire should affect measurements equally in patients and providers, and thus the problems of the measure do not seem to justify the scarce correlation observed.

In study IV, the main limitations depended on the need of pooling together different conditions. However, the different oral mucosal conditions were joined with the purpose of creating groups as homogeneous as possible in terms of diagnosis, or at least in terms of clinical problems posed to the dermatologist.

Concluding remarks
This thesis showed a low agreement between patient and provider in the evaluation of quality of life and psychological problems of patients, and of the disease severity, both in dental and dermatological conditions. The discrepancies were both in the direction of an underestimation and an overestimation by the caregiver.

This shows that there is a real need for dental and dermatological care providers of being able to communicate effectively with their patients in order to build a positive rapport and trust. Our results suggest that it may be important to provide dentists and dermatologists with improved training in patient-caregiver communication, which could increase patient satisfaction and ultimately result in better care.
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I wish also to thank all caregivers and patients who participated in the study for their essential collaboration.
REFERENCES


APPENDIX

Study I
Study II
Study III
Study IV