Patient reported outcomes in chronic skin diseases: eHealth applications for clinical practice
van Cranenburgh, O.D.

Citation for published version (APA):
van Cranenburgh, O. D. (2016). Patient reported outcomes in chronic skin diseases: eHealth applications for clinical practice

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: http://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
Chapter 9

GENERAL DISCUSSION
MAIN FINDINGS

This thesis aimed to examine and integrate patient reported outcomes (PROs), such as health related quality of life (HRQoL) and treatment satisfaction, in dermatological care. We have shown that patients with lichen sclerosus (LS) and lichen planus (LP) experience an impaired HRQoL. Although patients with various chronic skin diseases were overall positive about the dermatological care provided by nurses and doctors, patients with psoriasis, LS and LP were only moderately satisfied with their current treatment.

To integrate PROs in dermatological care, we developed and tested two eHealth applications: PROM portal Dermatology and E-learning Quality of Life. Although important stakeholders evaluated both applications as relevant, implementation in clinical practice and patients’ daily life was not easy.

DISCUSSION OF FINDINGS

Introduction of a stepped care model

Following our studies, we propose a stepped care model to stimulate the use of PROs in clinical dermatological practice and to provide patients with appropriate care. Stepped care means that care is provided in steps or stages, starting with the least intensive and least expensive intervention. The next step, i.e. more complex care, is chosen only when the previous step was evidently not appropriate, when it was insufficient, or when it failed. To evaluate whether treatment goals are reached or whether a next step is indicated, outcomes should be routinely measured. Stepped care is a widely used method in mental health care and is considered to be a cost-effective, efficient and tailored way of providing care. In somatic chronic diseases such as diabetes, asthma and COPD, a stepped care approach for the treatment of depression and anxiety appeared to be effective as well.

Our proposed stepped care model for chronic skin diseases consists of the following three steps: 1) Dermatological treatment, 2) Dermatological treatment & blended HRQoL patient education, and 3) Dermatological treatment & psychosocial treatment (Figure 1). Systematic PRO measurement is applied to routinely measured outcomes during each step and to determine whether a next step is indicated.

Step 1: Dermatological treatment

Patients with a chronic skin disease receive dermatological care based on the state-of-art knowledge as defined in (inter)national clinical guidelines. As chronic skin diseases cannot be cured, dermatological treatment may only result in a temporary suppression of physical symptoms. Patients do not only have to cope with physical symptoms, but may also experience psychosocial problems. Thus, adjustment of dermatological treatment and/or additional care may be needed to improve patients’ HRQoL and to reduce disease burden. We propose PRO measurement to signal the need for adaptations of and/or additions to the care provided.
Step 2: Dermatological treatment & blended HRQoL patient education

As patient education may lead to improvement of HRQoL in chronic skin diseases and as web-based interventions have several advantages, we propose web-based HRQoL patient education as a promising strategy to provide additional care. To be successful, the intervention has to meet patients’ needs, has to be effective in improving HRQoL, and should be feasible and efficient.

As non-adherence is a well-known problem in web-based interventions and as blended care appears to be a key element to motivate patients, we propose to apply blended care. We recommend to start with a face-to-face intake consultation by a nurse, nurse practitioner, skin therapist or by other supporting personnel. During this consultation, we advise to apply motivational interviewing, i.e. a method to facilitate and engage a patient’s intrinsic motivation in order to change behavior. During the web-based intervention, we recommend periodical contact between health care provider and patient through telephone or e-mail. The frequency and way of contact needs to be described in a blended care protocol. Moreover, we propose to develop a training for
involved health care providers about the intervention itself, its relevance, the blended care protocol and motivational interviewing. After the patient completes the educational intervention, we again propose PRO measurement to evaluate whether treatment goals are reached or whether the next step is needed.

**Step 3: Dermatological treatment & psychosocial treatment**

In some patients, referral to a psychosocial care provider is appropriate as additional care. We propose PRO measurement to determine whenever this is the case. Referral to a psychosocial care provider may occur immediately after step 1 or after failure of step 2. Psychosocial care may be provided by a psychologist, psychiatrist, social worker or other psychosocial care provider.

To be able to adequately refer patients to a psychosocial care provider, information about referral possibilities has to be transparent and accessible to health care providers. Moreover, the psychosocial care provider needs to be knowledgeable about psychosocial problems specific for skin patients and about relevant treatment approaches. According to stepped care, after referral to and treatment by a psychosocial care provider, the patient again completes PRO measurement to evaluate whether the treatment objectives are achieved.

**(Web-based) PRO measurement**

PRO measurement is an essential and recurrent element of our stepped care model. Routinely measured PROs can reveal the burden of disease, the possible need to adjust dermatological treatment and/or to provide additional care. Web-based measurement may have several advantages and may facilitate integration in routine care. PRO measurement is invaluable, as PROs directly reflect the voice of the patient. Moreover, the association between PROMs and clinical measures is poor\textsuperscript{14-16}. Therefore, we propose (web-based) PRO measurement to determine which step is appropriate for a specific patient.

For adequate routine PRO measurement, there needs to be consensus among health care providers about which PROM(s) to apply. Also, PRO measurement should be relevant in the opinion of all stakeholders and feasible in routine practice. Moreover, the psychometric quality of the PROM(s) has to be ensured, and the interpretation of PROM scores should be clear. For adequate interpretation of scores, validated cut-off scores are needed. For the Skindex-29, cut-off scores are currently available, enabling interpretation of scores as mild, moderate, and severe HRQoL impairment\textsuperscript{17,18}. When a score is categorized into moderate or severe impairment of HRQoL, this still does not tell us what to do. Therefore, we recommend to develop a decision tree for clinical practice, involving validated cut-off scores and suggestions for evidence-based effective care.

**Decision tree**

To support routine PRO use in clinical practice, we propose to develop a decision tree for health care providers. In this decision tree, scores of PRO measurement are categorized based on validated cut-off scores and serve as input to determine a suitable next step, see Figure 2 for an example. In a proportion of patients, PRO measurement
will reveal that the patient experiences no or little HRQoL impairment, which may lead to the advised step of continuation of the current dermatological treatment or to adjustment of the dermatological treatment. In other patients, PROMs results may indicate that the patient experiences moderate HRQoL impairment. In those instances blended HRQoL education is advised as a next step, in addition to continued or adjusted dermatological treatment. In a small proportion of patients, HRQoL impairment is severe, indicating appropriateness of professional psychosocial care, also in addition to continued or adjusted dermatological treatment.

As the degree of HRQoL impairment does not automatically correspond with a patients’ actual need for additional care and his/her willingness to undergo additional care, we propose that the health care provider and patient discuss the results of the PRO measurement and the proposed next step. During this consultation, the patient’s need for additional care and the patient’s willingness to undergo the next step should be explicitly addressed to enable a shared decision about the most appropriate care. We recommend that the health care provider applies motivational interviewing to engage the patient’s intrinsic motivation for the next step.

As training appeared to be essential for successful implementation of PRO measurement in clinical practice\textsuperscript{19-21}, we also recommend to develop a training for health care providers on the relevance of PRO measurement, interpretation of PRO scores, application in clinical practice, use of the decision tree and communication tools for shared decision making and motivational interviewing.

**The stepped care model: where are we now and where we should be going?**

For each step of the stepped care model, we will discuss the limitations and implications of our studies in light of the literature, and future directions for clinical practice and research (see Table 1).

**Step 1: Dermatological treatment**

Although patients with a chronic skin disease were overall positive about the care provided by doctors and nurses (Chapter 4), many patients appeared not to be satisfied with their current treatment (Chapters 2, 3a and 3b). For patients, effectiveness of treatment was most important, as was reported by others\textsuperscript{22}. Based on patients’ experiences, we recommended to improve quality of care by focusing on information provision by healthcare providers, accessibility of care and patient involvement. Information provision by health care providers was identified by others as priority for improvement of dermatological care\textsuperscript{23}, and could for instance be supported by leaflets and websites. Patient involvement may be improved by educating health care providers in shared decision making and interpersonal skills, in particular the dermatologist’s ability to demonstrate concern for the patient’s health, to answer a patient’s questions, and to provide explanations for the skin problem, as those skills have previously been associated with patient satisfaction\textsuperscript{24}.

Current clinical guidelines mostly describe the effectiveness and safety of available treatments. However, from a patient perspective, other aspects of treatment and care may be of importance as well, e.g. treatment convenience, information provision about the treatment, organization of treatment and doctor-patient communication. Currently,
Figure 2
Concept decision tree using the level of HRQoL impairment to determine a suitable next step
Table 1
The stepped care model: state-of-art and future directions

<table>
<thead>
<tr>
<th>Where are we now?</th>
<th>Where should we be going?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Step 1:</strong> Dermatological treatment</td>
<td>Improve quality of care: focus on information provision, accessibility of care, patient involvement</td>
</tr>
<tr>
<td>• Many patients are dissatisfied with their current treatment</td>
<td>• Include other indicators of quality of care in clinical guidelines: convenience, information provision, organization of treatment, doctor-patient communication</td>
</tr>
<tr>
<td>• Clinical guidelines focus on effectiveness and safety of treatments</td>
<td></td>
</tr>
<tr>
<td><strong>Step 2:</strong> Dermatological treatment &amp; blended HRQoL patient education</td>
<td></td>
</tr>
<tr>
<td>• HRQoL of patients with a chronic skin disease is impaired</td>
<td>• Provide patients with additional psychosocial care to support them in coping with their skin disease</td>
</tr>
<tr>
<td>• Implementation of <em>E-learning Quality of Life</em> in patients’ daily life is difficult</td>
<td>• Study how to improve adherence to e-learning</td>
</tr>
<tr>
<td></td>
<td>• Offer blended learning and training for health-care providers</td>
</tr>
<tr>
<td></td>
<td>• Identify the primary target group of e-learning</td>
</tr>
<tr>
<td></td>
<td>• Study (cost-)effectiveness of e-learning</td>
</tr>
<tr>
<td><strong>Step 3:</strong> Dermatological treatment &amp; psychosocial treatment</td>
<td></td>
</tr>
<tr>
<td>• A wide gap exists between patients’ indications for referral to a psychosocial care provider and actual referral rates</td>
<td>Increase awareness among dermatologists about psychosocial problems of patients with a chronic skin disease</td>
</tr>
<tr>
<td>• There is sufficient interest in psychodermatological training among psychosocial care providers</td>
<td>• Provide transparent and accessible information about referral possibilities to psychosocial care</td>
</tr>
<tr>
<td></td>
<td>• Develop training in psychodermatology for psychosocial care providers</td>
</tr>
<tr>
<td><strong>(Web-based) PRO measurement &amp; decision tree</strong></td>
<td></td>
</tr>
<tr>
<td>• There is no consensus on PROMs of choice</td>
<td>Reach consensus on PROMs of choice</td>
</tr>
<tr>
<td>• Psychometric quality of Skindex-29 is known, of our treatment satisfaction questionnaire not</td>
<td>Study psychometric quality of existing instruments more extensively</td>
</tr>
<tr>
<td>• Cross-cultural validation of existing PROMs is unknown</td>
<td>• Develop and validate a decision tree for clinical practice with validated cut-off scores and suggestions for evidence based effective care</td>
</tr>
<tr>
<td>• Interpretation of PROM scores is not self-evident</td>
<td>• Study ways to improve implementation of the web-based PROM portal</td>
</tr>
<tr>
<td>• Implementation of web-based PRO measurement in clinical practice is difficult</td>
<td>• Develop a shared decision making protocol and training for health care providers</td>
</tr>
</tbody>
</table>
in several Dutch clinical guidelines, e.g. on psoriasis, lichen sclerosus, lichen planus and acneiform dermatoses, information on HRQoL and treatment satisfaction is already included. We hope that guidelines for other skin diseases will follow.

Step 2: Dermatological treatment & blended HRQoL patient education

It is well-known that HRQoL is impaired in many patients with chronic skin diseases. We confirmed this in Chapters 3a and 3b, showing that one third of patients with LS and LP experienced a severely impaired HRQoL. Thus, there is a need to address patients’ disease burden and support them in improving their HRQoL.

We developed a web-based, educational, HRQoL intervention for patients with a chronic skin disease, E-learning Quality of Life. This intervention has the potential to be an effective, efficient, tailored and patient-centered way to provide additional care. As we have shown in Chapter 7, implementation of the E-learning Quality of Life in routine practice was feasible and acceptable to health care providers, however, implementation in patients’ daily life turned out to be less feasible. Even after adjusting the intervention itself, its relevance and feasibility were still rated low by patients (Chapter 8).

For future research we therefore suggest to study how to improve the intervention itself to better meet patients’ needs and to increase adherence to the intervention. A meta-analyses of self-guided web-based interventions for depression concluded that male gender, lower educational level and co-morbid anxiety symptoms significantly increased the risk of dropping out. It is worthwhile to study whether the same predictors for drop-out can be found in our intervention.

Moreover, we recommend to further study the attitudes and characteristics of the individuals involved, i.e. health care providers and patients, to be able to better specify the target group of our intervention and to use this input in our implementation strategy. After those adjustments in the intervention, and after specifying the target group, it is important to study the intervention’s (cost)effectiveness and to evaluate the blended care protocol and training for health care providers.

Step 3: Dermatological treatment & psychosocial treatment

In the Netherlands, a study among 144 dermatologists concluded that they referred on average 8 patients per year to a psychosocial care provider, and about 35% of them never referred patients to a psychosocial care provider. As approximately 25-50% of adult patients with a skin disease suffer from heightened levels of psychological distress, and patients with a skin disease have a higher risk for depression, anxiety disorder and suicidal ideation compared to the general population, it is clear that a wide gap exists between patients’ indications for referral to a psychosocial care provider and actual referral rates.

Thus, it is important that dermatologists become more aware of the degree of psychosocial problems of patients with a chronic skin disease. Information about referral possibilities to psychosocial care is currently not transparent and accessible to dermatologists, so this has to be improved. Moreover, we suggest to develop specific education in psychodermatology for psychosocial care providers. There appears to be sufficient interest in such education among psychosocial care providers.
(Web-based) PRO measurement

As mentioned before, consensus among health care providers about the instrument of choice is preferred to enable adequate comparisons of scores and synthesis of data. The psychometric quality is crucial in choosing an instrument. Although we used the Skindex-29 as instrument of choice (Chapters 3a, 3b, 5, 6), in accordance with several reviews, there is no consensus yet in dermatology which HRQoL instrument is best. For treatment satisfaction (Chapters 2, 3a, 3b) and patient experiences (Chapter 4), we developed two new questionnaires, as no such instruments were available in dermatology. The psychometric quality of our treatment satisfaction questionnaire is not studied yet. We studied several psychometric aspects of the Consumer Quality Index Chronic Skin Diseases (CQI-CSD) (Chapter 4), but not its test-retest reliability. Also, the cross-cultural validation of the instruments we used is not known. Thus, with respect to psychometric quality of these PROMs, more research is needed.

For routine PRO measurement, an instrument’s usability is essential. In Chapter 4, we revised the CQI-CSD based on psychometric characteristics and stakeholders’ input. The revised instrument still consists of 65 items, which appears to be too long for routine measurement in clinical practice. With respect to the Skindex-29, the treatment satisfaction questionnaire and the question on disease severity, we found that completion took less than 5 minutes (Chapter 6) which is, in our opinion, acceptable for routine use. However, implementation of the PROMs portal Dermatology appeared to be only moderately feasible and results of PRO measurement were hardly discussed during consultations (Chapter 6). The barriers we found, i.e. lack of time and personal capacity, were also reported by others.

To have a meaningful impact on patient care, the collection of and reporting of PROs must be done with minimum burden and maximal clinical relevance. Several recommendations to enhance the implementation of PRO measurement in clinical practice are proposed, for instance: to integrate PRO collection in the clinical workflow; to involve clinicians to develop a format for reporting PRO results in an understandable, clear and actionable way; to incorporate PRO results directly into the electronic health record. From palliative care, we know that successful implementation of PRO measurement is facilitated by having a coordinator throughout the implementation process, addressing cognitive/emotional processes of each involved individual, and education of the involved health care providers prior to implementation. Also, it appeared that health care providers value PROMs when they are useful for clinical decision-making and that interpretability of PROMs increases their use. Therefore, we aim to increase the value for professionals and to facilitate implementation of PRO measurement by the development of a decision tree, a shared decision making protocol and a training for health care providers.

Decision tree

The development of our proposed decision tree is not self-evident, but requires validation studies to determine cut-off scores. Although cut-off scores are available for the Skindex-29, such information is not available for our treatment satisfaction and CQI-CSD questionnaires. Moreover, the decision tree itself has to be tested and validated before it may be of use in clinical practice.
Implementation of the stepped care model in clinical practice
The implementation of our two eHealth applications proved to be challenging. We recommend to implement both applications together, as an integral part of our stepped care model. From implementation science, we know the importance of not only focusing on characteristics of the intervention, but also on the individuals involved, the inner/outer setting and the process by which implementation is accomplished. We therefore recommend to actively involve patients, professionals, and health care organizations, as did others, and to continuously evaluate the implementation process in a plan-do-study-act cycle. Furthermore, future research is needed to evaluate the implementation and effectiveness of the stepped care model.

CONCLUSION
In this thesis we gained more insight into the impact of chronic skin diseases on patients' HRQoL, patients' treatment satisfaction, and their experiences with care. Although considered relevant, eHealth applications appeared to be difficult to integrate in clinical practice. However, we still think that eHealth offers a promising and efficient strategy to provide additional care if all stakeholders' needs are taken into account. We proposed a stepped care model to integrate PROs in clinical dermatological practice and provide patients with appropriate care. Also, we offered suggestions for future research and clinical practice. Hopefully, this thesis contributes to the integration of PROs in dermatological practice, thereby enhancing patient-centered and personalized care.
REFERENCES


55. Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare: a system-

