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

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Chapter 1

GENERAL INTRODUCTION
INTRODUCTION

Chronic skin diseases are prevalent and have a profound influence on patients’ lives
Although chronic skin diseases, such as psoriasis, atopic dermatitis, vitiligo and leg ulcers, are not immediately life-threatening, they have a profound influence on patients’ lives. Globally, skin diseases are the fourth leading cause of nonfatal disease burden. In the Netherlands, skin diseases account for 12.4% of all diseases seen by general practitioners with especially high prevalence rates for example psoriasis (15.9%) and atopic dermatitis (24.8%). Moreover, the number of patients with a skin disease, such as leg ulcers and skin cancer, is increasing due to ageing of the population and lifestyle, i.e. sun exposure. Examples of physical symptoms of chronic skin diseases are itch and pain. Dermatological treatment may result in a temporarily suppression of those symptoms only, since chronic skin diseases cannot be cured. Consequently, patients have to cope with the burden of their skin disease for years, or sometimes even their entire life.

Patients with a chronic skin disease are also likely to experience psychosocial consequences, such as depression, anxiety, embarrassment, problems with work, personal relations or sports. Approximately 25-50% of adult patients with a chronic skin disease suffer from heightened levels of psychological distress. Compared to the general population, they have a higher risk for depression, anxiety disorder and suicidal ideation. Psychological distress in turn may negatively influence the course of their disease. Several studies have shown that stress may lead to an increased disease severity and impair disease clearance. Thus, patients may end up in a negative vicious cycle.

Patient reported outcomes are valuable on an individual and aggregated level
Patient reported outcomes (PROs) are assessments of any aspect of a patient’s health status and/or treatment impact that are directly expressed by the patient, i.e. without the interpretation of others. Examples of PROs are: symptoms, (health-related) quality of life, patients’ experienced disease severity, treatment adherence, and satisfaction with care. PROs are commonly measured by standardized, self-administered questionnaires: patient reported outcome measures (PROMs).

The importance of PROs and PROMs is increasingly acknowledged in healthcare, as they directly reflect the voice of the patient. Although many dermatologists think they have good insight into the impact of disease on their patients, the concordance between clinician-reported measurements of disease burden and PROMs appears to be poor. Thus, the use of PROMs in research and clinical practice may reveal physical and psychological problems that might otherwise be overlooked.

PROMs may serve several functions. Health care providers may use PROMs to screen an individual patient for problems, to monitor a patients’ health over time, to evaluate the effectiveness of a treatment and modify treatment if needed, to facilitate doctor–patient communication and to promote shared decision making. In this way, PROMs facilitate personalized healthcare, i.e. “tailoring the diagnosis, management and treatment of each patient to his or her individual characteristics” (p.149, Evers et al 2014).

At an aggregated level, PROMs may also be valuable to evaluate a clinic’s quality of care over time, or to compare the quality of care across clinics and/or providers. In
a system of regulated competition, all stakeholders need comparable information about health care providers’ performance in terms of effectiveness, safety and patient experiences. Therefore, to evaluate treatment quality or quality of care, a mix of clinician- and patient-reported outcome measures is recommended.

Health-related quality of life, treatment satisfaction and patient experiences with care are important PROs

Health-related quality of life (HRQoL), i.e. patients’ physical, psychological and social functioning, and well-being, is a well-acknowledged PRO and is increasingly becoming a standard outcome in healthcare and clinical studies. For patients, improvement of HRQoL is an important treatment goal. For highly prevalent skin diseases, such as psoriasis and atopic dermatitis, it is well-known that HRQoL is impaired and that the degree of impairment is comparable to other chronic diseases. For some less frequent skin diseases, such as lichen sclerosus and lichen planus, patients’ HRQoL is less thoroughly studied. It is important to gain more insight into the HRQoL of these patient groups to reveal the problems they encounter in daily life and to be able to provide them with the care they need.

Another PRO is patients’ treatment satisfaction. Treatment satisfaction is important as higher satisfaction may lead to improvement in HRQoL. In contrast, dissatisfaction may result in poor adherence, which is a widely acknowledged problem in dermatology, and as a consequence may lead to suboptimal health outcomes. Knowledge about treatment satisfaction may also provide information for specific actions to improve the quality of care. Measuring treatment satisfaction however also has some limitations, such as social desirable responding and ceiling effects, i.e. a high proportion of patients reporting maximum scores. To date, data on treatment satisfaction in patients with chronic skin diseases such as psoriasis, lichen sclerosus and lichen planus, are sparse.

To measure quality of care from the patients’ perspective, questions about patients’ experiences with care are nowadays preferred over questions about satisfaction, as the answers to these questions are supposed to be less influenced by subjective expectation or benevolence towards the caregiver and to provide a more discriminating measure of a healthcare organization's performance. In the Netherlands, the standard for the measurement of patient experiences with healthcare is the Consumer Quality Index (CQ-index or CQI). A CQI consists of questions to assess patient experiences with respect to relevant quality aspects, and questions to measure the importance that patients attach to these aspects. Information obtained with the CQI can be used by different stakeholders and for multiple purposes. For instance, CQI information can be used by healthcare providers to measure their provided health care and to initiate improvement projects, or by insurance companies in their negotiations with healthcare providers. To date, no standardized CQ-index exists for dermatology. Therefore, we developed the CQ-index Chronic Skin Disease (CQI-CSD) and examined its psychometric characteristics.
eHealth might support the integration of patient reported outcomes in dermatological practice

Although measuring PROs in patients with chronic skin diseases is relevant, the question still remains how to integrate PROs in daily dermatological care. Moreover, once it is determined that a patients' HRQoL is impaired, it is also important to find ways to improve HRQoL, for instance by providing additional care. One possibility to integrate PRO measurement in dermatological care and to provide additional care is by means of eHealth, i.e. the use of new information- and communication technologies, in particular internet technology, to support or improve health and healthcare. In the Netherlands, almost all health care users (93%) have access to the internet. Thus, eHealth applications have the potential to reach a large number of patients and healthcare providers. Moreover, eHealth is an important way to support patients' self-reliance, empowerment and self-management. In this thesis, we will focus on web-based PRO measurement and web-based HRQoL patient education.

Web-based PRO measurement

In several specialisms in healthcare, such as oncology, PROMs are increasingly assessed through computers, smartphones and tablets. Compared to paper-and-pencil questionnaires, electronic assessment has many advantages, such as shorter completion time, fewer missing responses, immediate and automatic calculation of scores enabling graphical feedback and/or automated alerts, and the possibility to digitally link results to an electronic patient record or to automatically store data in a database. However, electronic assessment may also have disadvantages, such as technical problems, the necessity of resources (e.g. staff, accommodation, hardware), and the need for patients to have basic computer skills. Despite those possible disadvantages, web-based PRO measurement might be a promising and efficient strategy to integrate PROs in dermatological practice.

Web-based HRQoL patient education

An effective means to improve HRQoL and to reduce disease severity of patients with chronic skin diseases is patient education, i.e. the provision of information with the aim of empowering patients and carers to solve problems arising from chronic diseases. Web-based educational interventions may have many advantages, for instance they can circumvent literacy problems by using visual and auditory aids, enable patients to work at self-moderated paces, and minimize the amount of time spent by physicians. Possible disadvantages of web-based interventions are the necessity for patients to have basic computer skills, lack of face-to-face contact with a healthcare provider and high drop-out rates. In a review of e-health interventions aiming at improvement of self-management of chronically ill patients, better clinical health outcomes were found when offered in addition to, or instead of, usual face-to-face care. In conclusion, web-based HRQoL patient education might be a promising and efficient strategy to improve HRQoL and to meet patients’ needs in addition to dermatological treatment.
Aims and outline of the thesis
The overall aim of this thesis is to examine and integrate patient reported outcomes in dermatological care. The thesis consists of two parts.

Part I: Patient reported outcomes in chronic skin diseases
In Part I, we examine HRQoL, treatment satisfaction, and experiences with care in patients with chronic skin diseases. In the first chapter of this part (Chapter 2), we aim to examine psoriasis patients’ satisfaction with different treatment types. In a cross-sectional study, members of two Dutch psoriasis patient associations (n=1200) completed a study-specific, web-based survey about their current and past treatment, treatment satisfaction and background characteristics.

In Chapters 3a and 3b we examine treatment satisfaction and HRQoL of patients with lichen sclerosus (LS, Chapter 3a) and lichen planus (LP, Chapter 3b). In a cross-sectional study, members of the Dutch LS Patient Association (n=303) and Dutch LP Patients Association (n=38) completed a web-based survey, consisting of a study-specific questionnaire on treatment satisfaction and the Skindex-29, a dermatology-specific HRQoL questionnaire.

In Chapter 4 our objective was to evaluate psychometric characteristics of a new questionnaire, the Consumer Quality Index Chronic Skin Diseases, to measure quality of care from patients’ perspective, and to explore patient experiences with care for chronic skin diseases. In a cross-sectional study, randomly selected adult patients in 20 hospitals (n=1160) who received dermatological care in the past 12 months filled out the questionnaire. We analyzed the dimensional structure, internal consistency and discriminative power of the questionnaire, explored patient experiences with dermatological care, and optimized the questionnaire based on the psychometric results and input of stakeholders.

Part II: Integrating patient reported outcomes in dermatological practice using eHealth
In Part II we aim to integrate PROs in dermatological practice. In Chapter 5 we intend to contribute to the discussion about and the implementation of HRQoL assessment in routine dermatological practice. We describe the relevance and target group of HRQoL assessment in dermatology. Taking electronic assessment of the Skindex-29 as an example, we give practical information for implementation of HRQoL assessments in routine practice.

In Chapter 6 we examine the relevance and feasibility of implementing the PROM portal Dermatology, a web-based application to electronically assess PROs in dermatological practice. In a feasibility study in 3 dermatological centers, professionals (n=9) and patients (n=80) completed study-specific questionnaires about the relevance and feasibility of the portal.

In Chapter 7 we aim to examine the feasibility and acceptance of implementing the E-learning Quality of Life, a web-based, educational, HRQoL intervention for patients with a chronic skin disease, in clinical practice and in patients’ daily life. In an observational pilot study in 6 dermatological centres, involved professionals (n=9) and patients (n=105) completed study-specific questionnaires about feasibility and acceptance of the intervention.
In **Chapter 8** we present an upgraded version of the *E-learning Quality of Life* and share patients’ and professionals’ first experiences. We tested the upgraded version in three dermatological centres and one patient organization. Patients (n=30) and professionals (n=15) completed a study-specific questionnaire about their experiences.

The thesis concludes with a general discussion (**Chapter 9**), reflecting on the main findings and future perspectives, and a summary (**Chapter 10**).
REFERENCES

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