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
Chapter 8

EXPERIENCES WITH A WEB-BASED, EDUCATIONAL, QUALITY-OF-LIFE INTERVENTION FOR PATIENTS WITH CHRONIC SKIN DISEASE

implementation is not easy!
SHORT COMMUNICATION

It is well-known that chronic skin diseases have a negative impact on patients' health-related quality of life (HRQoL). Patient education via internet is a promising way to efficiently and effectively provide care in addition to dermatological treatment, thereby improving patients' HRQoL. By introducing a web-based, educational, HRQoL intervention (E-learning Quality of Life, EQoL) we aimed to support patients in coping with their skin disease more effectively and to improve their HRQoL. This intervention was developed and tested in a feasibility study, published in this journal. The results of this study stimulated us to upgrade and extend the intervention. In this letter, we present this version alongside with our experiences with its implementation.

Development of the upgraded EQoL intervention

The first version of the intervention covered six educational topics: Itch, Worries, Anger, Depression, Social Contacts and Leisure Time. See Van Cranenburgh et al. for further details. Following our feasibility study, we concluded that we had to adjust the intervention to better match individual patients' needs to increase its relevance and feasibility.

The new version was set up as a modular course, i.e. the content of the intervention is presented step-by-step, thereby dosing the information and preventing patients from skipping pages. To match this new format, we developed an Introduction module, a Concluding module and six modules of choice, based on the content of the above-mentioned existing topics. In the Introduction module the concept of quality of life is explained and basic information about the intervention is given. The modules of choice contain tips and advice of both patients and experts, as well as tests and exercises concerning the module's topic. In the Concluding module, the patient reflects on what he/she has learned and makes a plan for the future.

Furthermore, we gathered new input from patients with various chronic skin diseases and experts of various disciplines, such as a dermatologist, psychologist and sexologist, by asking them to give specific advice based on their experience. We developed two extra modules, Body Image and Sexuality, using input of both patients and experts. As a result, the upgraded version consists of the following eight modules of choice: Coping with itch, Coping with anger, Coping with depression, Worrying, Social contacts, Leisure time and sports, Body Image and Sexuality.

We made several other adjustments to improve the feasibility. First, the upgraded intervention was made computer-tailored, i.e. the information was adjusted to individual characteristics to meet the patient's unique needs. Second, we added reminders via e-mail, automatically sent after three weeks inactivity. Third, we added the possibility of personalized feedback and blended learning, i.e. the integration of complementary face-to-face and online learning approaches and technologies. Patients were able to share exercises with their healthcare provider, who could monitor the progress of their patients and provide personalized feedback. Fourth, we developed animations and audio recordings for all modules.

All content of the upgraded version was reviewed by patients and experts, leading to further adjustments. Finally, the intervention was technically constructed and patients tested dummy versions.
First experiences of patients and professionals
We perceived our final version as a strong improvement. We tested it in patients (N=45) and all professionals involved (N=16) from three dermatological centres and an eczema patient organization. We asked them to complete a study-specific questionnaire and measured patients’ website use by website statistics.

Although patients (N=30, response rate 67%) evaluated the content, convenience and attractiveness of the intervention positively, we found - much to our surprise - that the relevance and feasibility were still rated as low. Whereas a large proportion of patients (35/45, 78%) actually started the intervention according to website statistics, of which almost all (N=32, 92%) completed the introduction module, only a minority (N=9, 26%) completed the first module of choice and only one patient (3%) completed all modules within eight weeks. Moreover, patients hardly used the option to share information with their health care providers.

Professionals (N=15, response rate 94%) rated the intervention as useful (73%), would recommend the intervention to colleagues (87%), would like to keep using the intervention in the future (87%) and evaluated the functionalities of the intervention as convenient (60-72%). A minority of professionals indicated that it was burdensome to inform patients about the intervention (11%) and to register patients in their daily practice (33%).

Discussion
Whereas we felt that the upgraded version of the EQoL intervention was a significant improvement, it did not meet our expectations. Of course, we know that low adherence is one of the main issues in internet interventions, but by closely involving patients and experts in the development and by adding several functions to the intervention known to increase adherence, we hoped to have tackled relevant barriers for its use.

In trying to solve this puzzle, we had a much closer look at the existing literature on implementation science. When reading the Consolidated Framework For Implementation Research (CFIR), we realized that we had mainly focused on improving characteristics of the intervention itself, but were still neglecting the so-called inner and outer setting, the characteristics of the individuals involved and the implementation process itself.

Although eHealth is politically acknowledged as an essential part of our current and future healthcare system, it is far from integrated yet. There are still many economic, social and cultural barriers to be taken. Moreover, as our intervention involves patients and healthcare providers, both need to be fully motivated to use the intervention. From our results, it appears that health care providers are motivated, whereas patients seem less motivated. Furthermore, we don’t know which patients are mostly motivated: a low level of quality of life does not automatically concur with a high level of motivation to use online support tools. Therefore, we need to gain more insight into our target group, the healthcare providers as well as patients.

Future directions
Currently, the intervention is implemented in several other enthusiastic dermatological centers and patient associations in the Netherlands that came forward as we announced the intervention. We decided to start with those early adopters, i.e. individuals who are
open to new ideas and are highly motivated to try new approaches, and who can be distinguished from so-called laggards, i.e. more conservative individuals who need time or even persuasion before accepting changes\textsuperscript{10,11}. In a plan-do-study-act cycle\textsuperscript{12}, involving both patients and experts, we will continuously evaluate patients’ experiences to further improve the intervention itself and to identify which patients use the intervention and benefit most. In this way we will be able to evaluate, update and re-evaluate the intervention, the implementation process and to specify the target group. Also, we will further develop the blended learning aspects to better integrate the intervention in routine care. Thereby, we aim to contribute to the social and cultural acceptance and integration of eHealth in dermatology.

Conclusion
Thanks to our disappointing findings, we have looked deeper into the implementation literature, we have learned that an intervention as ours is not suitable for each patient and that we need to gain more insight into our target group. We decided to continue this potentially relevant addition to dermatological care as we are convinced that web-based patient education can improve HRQoL, and that it has the potential to reach large numbers of patients with minimal time investment of the clinician. Moreover, our healthcare system is increasingly focused on empowering patients and improving their self-management, self-care and self-efficacy. Our intervention fits into this development although it appears that implementation is not easy. We hope that others will profit from our experiences and reflections.

ACKNOWLEDGEMENT
The authors thank the participating patients and involved professionals of the following organizations: Academic Medical Center (Amsterdam), Oosterwal Center (Alkmaar), Amphia hospital (Breda), Dutch Eczema Patient Association (Vereniging voor Mensen met Constitutioneel Eczeem, VMCE). The authors also would like to thank Anne-Marie van Hasselaar for coordinating the development of the intervention, Daniel Sloohof for his contribution to data collection/analysis and Esmée Tensen for analyzing webstatistics.

Conflict of interest and funding
The authors declare no conflict of interest. The development of the intervention was financially supported by AbbVie, DSW Zorgverzekeringen, Huidpatiënten Nederland, LEO Pharma, Neutral (Unilever), Stichting Agis. The pilot test was financially supported by Huidpatiënten Nederland.
Chapter 8

REFERENCES


