

## SHORT COMMUNICATION

### Implementation of Web-based Education for Patients with Chronic Skin Disease

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Chronic skin diseases have a negative impact on patients' health-related quality of life (HRQoL). Patient education via the Internet is a promising means of efficiently and effectively providing care in addition to dermatological treatment, thereby improving patients' HRQoL (1–3). By introducing a web-based, educational, HRQoL intervention (E-learning Quality of Life, EQoL; [www.kwaliteitvanleven.nl](http://www.kwaliteitvanleven.nl)), we aimed to support patients in coping more effectively with their skin disease and to improve their HRQoL. This intervention was developed and tested in a feasibility study (4), which prompted us to upgrade and extend the intervention. The new version of EQoL is described here, together with our experiences with its implementation.

#### METHODS

The first version of the EQoL intervention covered 6 educational topics: Itch, Worries, Anger, Depression, Social Contacts, and Leisure Time (4). Following a feasibility study, we concluded that the intervention should be adjusted to better match individual patients' needs to increase its relevance and feasibility.

The new version of EQoL was set up as a modular course, i.e. the content 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 6 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 for both patients and experts, as well as tests and exercises concerning the topic of the module. In the Concluding module, the patient reflects on what he or she has learned and makes a plan for the future.

Furthermore, we gathered new input from patients with various chronic skin diseases and from experts in various disciplines, e.g. dermatologist, psychologist and sexologist, by asking them to give specific advice based on their experience. We developed 2 extra modules, Body Image and Sexuality, using the input of both patients and experts. As a result, the upgraded version of EQoL consists of the following 8 modules of choice: Coping with itch, Coping with anger, Coping with depression, Worrying, Social contacts, Leisure time and sports, Body Image, and Sexuality.

Several other adjustments were made to improve the feasibility of the intervention. First, the upgraded intervention was computer-tailored, i.e. the information was adjusted to individual characteristics to meet the patient's unique needs (5). Secondly, reminders via e-mail were added, to be sent automatically after 3 weeks' inactivity. Thirdly, the possibility of personalized feedback and blended learning, i.e. the integration

of complementary face-to-face and online learning approaches and technologies, were added (6). Patients were able to share exercises with their healthcare provider, who could monitor the progress of their patients and provide personalized feedback. Fourthly, animations and audio recordings were developed for all modules.

All content in the upgraded version was reviewed by patients and experts, leading to further adjustments. Finally, the intervention was technically constructed and patients tested dummy versions. The final version was perceived as a strong improvement. It was tested in patients ( $n=45$ ) and all professionals involved ( $n=16$ ) from 3 dermatological centres and an eczema patient organization. All participants were asked to complete a study-specific questionnaire and patients' website use was measured via website statistics.

#### RESULTS

Although patients ( $n=30$ , response rate 67%) evaluated the content, convenience and attractiveness of the intervention positively, they rated relevance and feasibility as low. Whereas a large proportion of patients (35/45, 78%) started the intervention according to website statistics, of whom 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 8 weeks. Moreover, patients hardly used the option to share information with their healthcare 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. Low adherence is one of the main issues with Internet interventions (7, 8). By closely involving patients and experts in the development of the intervention, and by adding several functions

that were known to increase adherence, we hoped to have tackled relevant barriers to its use.

In trying to solve this puzzle, we studied the existing literature on implementation science. When reading the Consolidated Framework for Implementation Research (CFIR) (9), we realized that we had focused mainly on improving characteristics of the intervention itself, but were 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 remains far from integrated. There are still many economic, social and cultural barriers to be overcome. 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 healthcare providers are motivated, whereas patients appear to be less motivated. In addition, it is not known which patients are most 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.

EQoL is currently being implemented in several other dermatological centres and patient associations in the Netherlands, which came forward when 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 (10, 11). In a plan–do–study–act cycle (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. Thus, we will be able to evaluate, update and re-evaluate the intervention, the implementation process and 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.

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