

INVESTIGATIVE REPORT

A Web-based, Educational, Quality-of-life Intervention for Patients with a Chronic Skin Disease: Feasibility and Acceptance in Routine Dermatological Practice

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Chronic skin diseases have a negative impact on patients' health-related quality of life (HRQoL). Patient education might contribute to HRQoL improvement. We developed a web-based, educational, HRQoL intervention for patients with a chronic skin disease. We aimed to assess 1) the feasibility of implementing the intervention in routine dermatological practice and patients' daily life, and 2) the acceptance of the intervention by health care providers and patients. Additionally, we aimed to create a patient user profile. We conducted an observational pilot study at 6 dermatological centres, including 105 outpatients. Implementation in routine practice was feasible and acceptable to health care providers. However, implementation in patients' daily life was found not to be entirely feasible. Perceived relevance by patients was low, though patients rated the intervention as convenient and attractive. No univocal user profile was found. Suggestions for improvements of the intervention, e.g. tailoring and adding blended learning components, are discussed. Key words: health-related quality of life; patient education; chronic skin disease; eHealth.

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Chronic skin diseases, such as psoriasis, atopic dermatitis, hidradenitis suppurativa, and vitiligo, have a relatively high, negative impact on the physical, psychological and social functioning, and well-being of patients (1–4), i.e. patients' health-related quality of life (HRQoL) (5). Dermatological treatment greatly contributes to the improvement of HRQoL, but may result only in a temporary suppression or remission of symptoms, as chronic skin diseases cannot be cured. By assessing HRQoL with a generic- or dermatology-specific HRQoL questionnaire (6), a potential need for adjustment of current dermatological treatment (e.g. more invasive treatment) and/or for additional support may be signalled (7). Additional support may be delivered through advice and counselling,

membership of a patient association, psychotherapy, or patient education.

Patient education can be defined as the provision of information with the aim of empowering patients and carers to solve problems arising from chronic diseases (8). Patient education thus entails helping patients to understand their disease and treatment, to engage them in management and care, to let them take responsibility for their health, and to foster a return to their normal, daily activities (9). In a variety of chronic diseases, such as hypertension, arthritis and asthma, patient education enables patients to manage their disease more effectively, to increase patient satisfaction, and to improve adherence and outcomes (10–14). Patient education can also enhance patients' self-esteem and feelings of empowerment, and may decrease isolation and hopelessness (15). In patients with chronic skin diseases, a systematic review of studies on the effectiveness of patient education pointed out that patient education can be effective in increasing HRQoL and in decreasing disease severity (8).

Given the tremendous increase of Internet users, web-based educational interventions have the potential to reach a large number of patients. Additionally, web-based interventions can eliminate literacy problems by using visual and auditive aids, and enable patients to work at self-moderated paces, while minimising the amount of time spent by physicians (16). 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 (17). Therefore, web-based patient education might be a promising and efficient strategy to improve patients' physical, psychological and/or social well-being, and to meet patients' needs in addition to dermatological treatment.

In cooperation with patients and health care providers, we developed a web-based, educational, HRQoL intervention for patients with a chronic skin disease: E-learning Quality of Life (EQoL). EQoL offers patients knowledge and skills to cope with their skin disease more effectively and to improve their HRQoL. See Methods-section and Tables SI¹ and SII¹ for further details.

Whereas the potential advantages of this eHealth intervention may be clear, practical barriers may hinder

an efficient and effective use in clinical practice. Feasibility of implementation of EQoL in dermatological practice and in patients' daily life, and acceptance of the intervention by health care providers and patients are important prerequisites. Therefore, to test and optimise the intervention before studying its effectiveness, we first conducted a pilot study.

The aim of this pilot study was to assess (i) the feasibility of implementation of the EQoL intervention in routine dermatological practice and patients' daily life, and (ii) the acceptance of the EQoL intervention by both health care providers and patients. We defined acceptance by patients as the perceived relevance, convenience and attractiveness of the intervention. Additionally, we aimed to create a user profile by examining to what extent patient characteristics predict patients' use and perceived relevance of the EQoL intervention.

MATERIAL AND METHODS

Participants

We aimed to include 5–10 dermatological centres in the Netherlands. We invited 11 dermatologists having participated in one of our previous HRQoL studies (18, 19) or having shown an interest in HRQoL otherwise. These dermatologists could be supported or replaced by a resident and/or nurse.

We aimed to include approximately 100 outpatients with various chronic skin diseases, visiting a general outpatient clinic for a first or a control visit. Inclusion criteria were: (i) diagnosis of a chronic skin disease, such as psoriasis, atopic dermatitis, acne, vitiligo, hidradenitis suppurativa; (ii) impaired HRQoL and/or a moderate to high motivation to improve their HRQoL, in the opinion of the health care provider; (iii) 18 years or older; and (iv) access to a computer with Internet connection. Eligible patients were consecutively invited by the participating dermatologists or supporting resident/nurse, who were instructed to include as many patients as possible during the inclusion period.

The present study was designed and conducted as an observational study. The central Ethics Committee of the Academic Medical Centre exempted this pilot study from ethical approval. For observational research, this is common policy in the Netherlands. The study was conducted according to the Declaration of Helsinki Principles of 1983.

Intervention

Our web-based, educational intervention (EQoL) offers patients knowledge and skills to cope with their skin disease more effectively and aims to improve their HRQoL. Patients can enter the website www.kwaliteitvanleven.nl at self-selected moments. EQoL consists of 6 components: itch, worries, anger, depression, social contacts and leisure time. Those components are derived from the Skindex-29, a well-established dermatology-specific quality-of-life questionnaire (20–23). The content of EQoL aims to match all stages of change as described in the Transtheoretical Model (24), i.e. from contemplation of behaviour change until maintenance. Patients can freely choose parts of the intervention that are relevant to their individual situation. See Tables SI¹ and SII¹ for further details.

Procedure

After consultation at the outpatient clinic, the patient completed a questionnaire on background characteristics and signed an informed consent form. At the same time, the health care provider completed a questionnaire about the patient. Subsequently, the researcher sent the patient an e-mail with a personal password to log into the website. Patients who had not visited the website during the first 2 weeks, received a reminder by e-mail. If needed, patients could contact a help desk. Eight weeks after inclusion, patients received a questionnaire by postal mail. Patients who did not return the questionnaire within 2 weeks received reminders by e-mail and/or telephone. During participation in the study, patients' control visits at the dermatology outpatient clinic were planned following routine clinical practice. At the end of the study, health care providers received a questionnaire by postal mail and a reminder by e-mail, if necessary.

Measurements

Feasibility. Feasibility in routine dermatological practice according to health care providers was measured with study-specific questions concerning the time spent on explaining the intervention to patients (2 items), on registering the patient (1 item) and regarding self-perceived feasibility (2 items), e.g. "Did you experience the time spent on explaining and registering the patient as a burden?" (5-point response scale ranging from "not at all" to "very much"). The time spent on explaining the intervention was measured for each included patient directly after consultation as well as at the end of the study. Mean scores of <3 were considered a reflection of sufficient feasibility. Additionally, health care providers were asked to give suggestions to further improve the implementation of the intervention.

Feasibility in patients' daily life was measured by asking patients whether their daily activities and/or skin care had hindered them to spend time on the intervention (2 items, 5-point response scale ranging from "not at all" to "very much"). Mean scores of <3 were considered a reflection of sufficient feasibility. Also, patients were asked to indicate how much time they had spent on the website in total. Furthermore, frequency and duration of website visits and specific webpage views of each patient were measured.

Acceptance. Health care providers' acceptance was measured by asking them to indicate to what extent they found the intervention a valuable addition to routine dermatological treatment, whether they would recommend the intervention to a colleague and whether they wished to continue using the intervention after completion of the study (3 items, 5-point response scale ranging from "not at all" to "very much" or "definitely not" to "definitely"). Mean scores of ≥ 3 were considered a reflection of sufficient acceptance.

Patients' acceptance was measured by asking patients to indicate how relevant the intervention was to them (10 items, e.g. "I have learned new skills through the intervention"; 5-point response scale ranging from "not at all" to "very much"). Furthermore, patients were asked to evaluate the convenience of the intervention (4 items, e.g. "I could easily find the information I was looking for"; 5-point response scale ranging from "not at all" to "very much"), and attractiveness of the design and lay-out of the website (5 items, e.g. "The colours of the website are..."; 5-point response scale ranging from "not nice at all" to "very nice"). By averaging the scores of the 10, 4 and 5 items, respectively, we calculated patients' reported relevance (Cronbach's α 0.95), convenience (Cronbach's α 0.88) and attractiveness (Cronbach's α 0.76). Mean scores ≥ 3 were considered a reflection of sufficient relevance, convenience and attractiveness, respectively. Additionally, we asked patients how they evaluated the letter font and length of texts (2 items, e.g. "The letter font is..."; 1: too small to 5: too big).

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Background characteristics

The usual demographic and clinical characteristics of patients were measured, e.g. date of birth, sex, diagnosis (see Table SIII¹). Patients' HRQoL was measured with one global item and the Skindex-29 (20–23), to be completed by the patient, and one global item to be completed by the health care provider.

Statistical analyses

All statistical analyses were performed in SPSS 19.0, using an alpha level of 0.05. Drop-outs and patients who were lost to follow-up were compared using independent *t*-tests, Mann-Whitney, and χ^2 analyses.

To determine the extent to which patient characteristics predicted website use, we performed a logistic regression model (Enter method) with age, sex, education level, diagnosis, HRQoL, and disease severity as predictors, and website visited (yes/no) as dependent variable.

To determine the extent to which website users' characteristics predicted frequency and duration of website visits and patients' experienced relevance of the intervention, we first categorised the 3 dependent variables into 3 categories, reflecting approximately equal numbers of respondents. We then performed ordinal regression analyses with age, sex, education level, diagnosis, disease severity from the patient's perspective and HRQoL as predictors and visit frequency, duration of website visits, and patients' experienced relevance respectively as dependent variables.

RESULTS

Participants

Six out of 11 (55%) dermatologists agreed to participate, representing 2 academic and 4 non-academic centres. Lack of time was the most common reason for non-participation. At the 6 study sites patients were recruited by 9 health care providers (6 dermatologists, 2 residents, and one research nurse). Patients were included from April until June 2011.

Of the patients invited by health care providers (number not known), 107 met eligibility criteria and agreed to participate. One patient did not complete the informed consent form and one patient completed less than 50% of the baseline questionnaire. The resulting 105 patients received a login for the intervention (Demographic and clinical characteristics, Tables I and SIII¹). Ten patients (9.5%) decided to withdraw before the end of the study (drop-outs), of whom 7 agreed to complete the follow-up questionnaire prematurely. Thirty-two patients (31%) did not return the follow-up questionnaires despite reminders

Table I. Patients' baseline HRQoL as measured with Skindex-29. Domain- and overall scores categorised by using cut-off scores as published by Prinsen et al. (18, 25) (*n* = 105)

	No impairment <i>n</i> (%)	Mild impairment <i>n</i> (%)	Moderate impairment <i>n</i> (%)	Severe impairment <i>n</i> (%)
Symptoms	34 (32.4)	4 (3.8)	20 (19.0)	47 (44.8)
Emotions	20 (19.0)	11 (10.5)	9 (8.6)	65 (61.9)
Functioning	34 (32.4)	12 (11.4)	7 (6.7)	52 (49.5)
Overall	25 (23.8)	11 (10.5)	18 (17.1)	51 (48.6)

(lost to follow-up). In total, follow-up questionnaires of 70 patients (67%) were used for further analyses.

Patient characteristics of drop-outs (*n* = 10) did not significantly differ from characteristics of non drop-outs (data not shown). Characteristics of patients who were lost to follow-up and of patients who returned their follow-up questionnaires were comparable, except for age (mean \pm SD) (37.6 \pm 12.1 versus 44.8 year \pm 13.2; *t* (103) = -2.7, *p* < 0.05) and disease duration (median 0.83 year, IQ range 0.08–1.75 versus median 1.92 year, IQ range 0.92–4.00; *U* = 1,562.50, *z* = 3.35, *p* < 0.05).

We were successful in including the target patients of our intervention (see Tables I and SIII¹): patients with various chronic skin diseases, an impaired HRQoL (71%) and/or a high motivation to learn more about HRQoL (43%) in the opinion of the health care provider. Fifty-one patients (49%) reported a severely impaired HRQoL, but also patients with no, mild or moderate HRQoL impairment were included.

Feasibility

According to health care providers, the time spent to explain the intervention was less than 5 min in the majority of patients (64%). At the end of study, most health care providers' (67%) indicated to have spent on average 5–10 min per patient (Table II). Self-perceived feasibility was sufficiently high: health care providers indicated that time spent was not a burden to them, neither was it difficult to integrate the intervention into their routine practice (Table II). The following suggestions for further improvement of implementation were made: (i) assistance by nurses in explaining the intervention to patients and by administrative assistants in registering patients, and (ii) informing patients about the intervention by mail before the consultation.

According to patients, implementation in their daily life was not feasible: patients indicated that their daily activities hindered them in paying attention to the intervention (Table II). The majority of patients (83%) visited the website one or more times, range 1–10 visits per patient (Table II). The following content was viewed most often by patients: homework/assignments (778 views, 18%), self-assessments (355 views, 8%), interviews with patients (213 views, 5%). Seven out of 70 patients (10%) reported technical problems concerning a login that did not work (*n* = 4) and printing (*n* = 3).

Acceptance

According to health care providers, implementation in routine practice was acceptable: health care providers rated the intervention as a valuable addition to routine dermatological treatment, would recommend it to a colleague, and wanted to keep using the intervention (Table III).

According to patients who visited the website one or more times, the perceived relevance of the interven-

Table II. Feasibility - health care providers and patients

Health care providers	
Time spent per patient on explaining the intervention and registering the patient (<i>n</i> = 104), <i>n</i> (%)	
0–1 min	15 (14.4)
1–5 min	52 (50.0)
5–10 min	28 (26.9)
10–15 min	7 (6.7)
> 15 min	2 (1.9)
Mean time spent per patient on explaining the intervention (<i>n</i> = 9), <i>n</i> (%)	
0 min	1 (11.1)
5–10 min	6 (66.7)
>15 min	2 (22.2)
Mean time spent on registering a patient, <i>n</i> (%)	
0 min	2 (22.2)
0–5 min	4 (44.4)
5–10 min	2 (22.2)
10–15 min	1 (11.1)
Experienced the time spent on explaining and registering the patient as a burden ^a (<i>n</i> = 9), <i>n</i> (%)	
1 = not at all	4 (44.4)
2	2 (22.2)
3	3 (33.3)
4	0
5 = very much	0
Difficult to combine explanation about and registration for the intervention with routine dermatological practice ^b (<i>n</i> = 9), <i>n</i> (%)	
1 = not at all	2 (22.2)
2	3 (33.3)
3	3 (33.3)
4	1 (11.1)
5 = very much	0
Patients	
My daily activities hindered the use of the intervention ^c (<i>n</i> = 67), <i>n</i> (%)	
1 = I totally disagree	9 (13.4)
2	8 (11.9)
3	13 (19.4)
4	21 (31.3)
5 = I totally agree	16 (23.9)
My dermatological treatment and/or skin care hindered the use of the intervention ^d (<i>n</i> = 67), <i>n</i> (%)	
1 = I totally disagree	38 (56.7)
2	10 (14.9)
3	13 (19.4)
4	5 (7.5)
5 = I totally agree	1 (1.5)
Website use patients (<i>n</i> = 87)	
Number of visits	
Mean ± SD [range]	3.2 ± 2.2 [1–10]
Median [IQR]	2 [4]
Duration per visit (min:sec)	
Mean ± SD [range]	12:47 ± 8:39 [1:41–40:07]
Median [IQR]	00:10:24 [00:12:36]
Total duration (h:min:sec)	
Mean ± SD [range]	00:43:02 ± 00:41:34 [00:01:41–03:20:36]
Median [IQR]	00:30:04 [00:58:38]
Total time spent on website (self-reported) (<i>n</i> = 66), <i>n</i> (%)	
< 1 h	29 (43.9)
1–4 h	31 (47.0)
4–8 h	4 (6.1)
> 8 h	2 (1.9)

^aMean ± SD: 1.9 ± 0.9, Median (IQR): 2 (2); ^bMean ± SD: 2.3 ± 1.0, Median (IQR): 2 (1.5); ^cMean ± SD: 3.4 ± 1.3, Median (IQR): 4 (2); ^dMean ± SD: 1.8 ± 1.1, Median (IQR): 1 (2).

tion was low (Tables III and SIV¹). Nevertheless, the intervention appeared to be acceptable to patients with respect to convenience and attractiveness.

User profile

Website (non) use: the multiple logistic regression model could not explain a significant amount of variance of website use (χ^2 (16) = 16.16, p = 0.442), no patient characteristic significantly predicted whether patients visited the website or not (data not shown).

Number of website visits: a significant ordinal regression model emerged with the predictors explaining 34% of variance (R^2 [Nagelkerke]) = 0.34, χ^2 (9) = 31.58, p < 0.05). Older patients visited the website significantly more often and patients with higher education visited the website significantly less often (Table SIV¹).

Total duration website visits: a significant ordinal regression model emerged with the predictors explaining 32% of the variance (R^2 [Nagelkerke]) = 0.32, χ^2 (9) = 28.44, p < 0.05). Older patients visited the website significantly longer (Table SIV¹).

Patients' perceived relevance: Scores were categorised into 'Low': ≤ 1.50, 'Medium': 1.51–2.80, 'High': ≥ 2.81. The ordinal regression model was not significant (χ^2 = 9.09, p = 0.43) and no patient characteristic significantly predicted patients' perceived relevance of the intervention (data not shown).

DISCUSSION

The results of our study suggest that implementation of the HRQoL intervention is feasible in routine dermatological practice, but not in patients' daily life. The intervention appeared to be acceptable to health care providers, but less acceptable to patients since they per-

Table III. Acceptance—health care providers and patients. Patients' answers on a 5-point scale (1 = totally disagree, 5 = totally agree)

	<i>n</i> (%)
Health care providers	
Valuable addition to routine dermatological treatment ^a (<i>n</i> = 9)	
1 = not at all	0
2	0
3	1 (11.1)
4	6 (66.7)
5 = very much	2 (22.2)
Recommend the intervention to a colleague ^b (<i>n</i> = 8)	
1 = definitely not	0
2	0
3	2 (25.0)
4	4 (50.0)
5 = definitely	2 (25.0)
Keep using the intervention ^c (<i>n</i> = 7)	
1 = definitely not	0
2	0
3	1 (14.3)
4	5 (71.4)
5 = definitely	1 (14.3)
Patients ^d	
Relevance (10 items ^e), <i>n</i> = 59	2.2 ± 0.9, 2.1 (1.6)
Convenience (4 items ^e), <i>n</i> = 55	3.9 ± 0.9, 4 (1.8)
Attractiveness (5 items ^e), <i>n</i> = 55	3.5 ± 0.7, 3.4 (0.8)

^aMean ± SD: 4.1 ± 0.6, Median (IQR): 4 (2); ^bMean ± SD: 4.0 ± 0.8, Median (IQR): 4 (1.5); ^cMean ± SD: 4.0 ± 0.6, Median (IQR): 4 (2); ^dMean ± SD, Median (IQR); ^eSee Table SIV¹.

ceived the relevance of the intervention as low, despite rating it as convenient and attractive. A univocal user profile based on patient characteristics was not found, although it appeared that older patients were more likely to use the intervention than younger patients.

We assumed that a patient-centred intervention such as ours would be welcomed by patients, so we were surprised by the low degree of feasibility and acceptance. Low adherence is considered one of the major methodological challenges in the evaluation of eHealth interventions (26). In a review of adherence to web-based interventions, it was reported that on average 50% of participants adhered to the intervention, with a wide range (<10–>90%) (27). Especially in self-management Internet interventions, users often drop out and a large proportion of patients never uses the intervention or uses it only once (26, 28–30). Patients generally report that the intervention does not fit into their daily life, despite their positive ratings of the intervention (31).

Our results raised serious concerns. Firstly, we asked ourselves whether we had made the purpose, the content and the time investment required for the intervention sufficiently clear to both health care providers and patients. Part of our sample had no or mild impairment in HRQoL, thereby raising questions about the selection made by health care providers.

Secondly, we wondered whether our intervention adequately matched patients' specific needs. We did not assess individual patients' needs. This is most likely an important omission, because an HRQoL intervention does not automatically fulfil patients' needs. Additionally, as our intervention was aiming at patients with a variety of chronic skin diseases, patients may not have recognised or identified their own specific skin disease. Finally, the intervention was limited to 6 components of HRQoL, not all of them being relevant to all patients.

Thirdly, we realised that patients with an impaired HRQoL do not necessarily feel the need to improve their HRQoL. An educational intervention such as ours requires patients willing to change their traditional attitude towards healthcare delivery, i.e. a switch from a more passive role as a recipient of health care services to a more active role. The more active role implies that the patient acquires a good understanding of the disease and its treatment, that he/she takes responsibility for his/her health, lifestyle and self-care. Patients' own efforts in terms of self-management and education are thus as crucial as dermatological treatment itself.

We concluded that, in order to increase patients' motivation to use the intervention, we should study individual patients' needs more thoroughly. Furthermore, we suggest several strategies to increase patients' use of our intervention. Firstly, computer-tailoring, i.e. the process of creating individualised messages by adjusting the information to individual characteristics to meet that person's unique needs (32), was previously reported as

an effective component in web-based interventions to promote healthy behaviour (30, 33). Secondly, personalised feedback and reminders via text-messages and/or e-mail were found to increase the use of web-based interventions (30, 34, 35). Thirdly, blended learning, i.e. the thoughtful integration of complementary face-to-face and online learning approaches and technologies (36), such as group meetings with patients, support of a nurse in face-to-face contacts or through telephone, may also improve patients' motivation. The interaction with a counsellor was previously found to improve adherence to web-based interventions (27, 37, 38).

Our study has several limitations. Firstly, selection bias may have occurred in our study sites. Study sites that showed an interest in HRQoL were included and, therefore, participating health care providers might be more motivated than other health care providers in dermatology in the Netherlands. Secondly, the number and characteristics of invited patients who were not willing to participate in the study were not reported. Therefore, we do not know whether our patient sample was biased, either positively or negatively.

In summary, we conclude that health care providers welcome the use of the HRQoL intervention in routine dermatological practice. However, a one-size-fits-all e-learning intervention does not appear to work. The intervention should be tailored to individual patients' needs, a more strict selection of moderately to highly motivated patients should be made, and/or motivation-increasing elements should be added to the intervention itself. The development of an improved version has been started. In close cooperation with several patient associations, the needs of patients are taken into account. Future research will focus on the effectiveness of the improved and extended intervention in improving HRQoL.

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