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Associations between disease education, self-management support, and health literacy in psoriasis

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ABSTRACT

Background: Patients' ability to perform self-management may be compromised if they are unable to fully comprehend their diagnosis and treatments. Weaknesses in health literacy (HL) pose a considerable health concern and may negatively influence SM, as well as interactions with health care professionals (HCP) and peers.

Objectives: To investigate possible associations between comprehensive HL and psoriasis education from HCPs in a cohort of patients with psoriasis. Another aim was to examine essential sources for psoriasis information and how these are evaluated.

Methods: Cross-sectional questionnaire data, including the comprehensive Health Literacy Questionnaire (HLQ) from 825 patients with psoriasis who had participated in Climate Helio Therapy (CHT).

Results: Participants having received HCP education scored significantly better in all HLQ scales compared to participants who did not receive such education (Cohen's effect size: 0.24 to 0.44). The CHT program, peers, and dermatologists were the most important sources of psoriasis information. People having participated more than once in CHT presented better HL scores and also higher self-management (skill and technique acquisition) and more psoriasis knowledge (effect-size: 0.75).

Conclusions: Psoriasis education by HCP seems important for HL and psoriasis knowledge. Patients may need multiple approaches and repetitions over time to be health literate and effective self-managers.

Introduction

In a complex autoimmune disease such as psoriasis, patients must understand multifaceted information related to treatment approaches (1), lifestyle choices (2), and self-management (3,4). Additionally, they must navigate the interplay between physical and psychological comorbidities (5–8) and therefore receive tailored knowledge from different sources to self-manage sufficiently. In a modern complex health care system, people with chronic conditions such as psoriasis are expected to participate in their health care, self-manage their disease(s), address their needs and navigate the different parts of the health care system (9). However, patients' understanding of psoriasis seems limited (10,11). Studies have shown that frustration with psoriasis treatment and management (12,13), detachment from health care services (14), and challenging adherence issues (15,16) are common among patients. Further, very few patients with psoriasis are aware of the risks associated with psoriasis (17). This may indicate that psoriasis information and education has the potential to be improved; however, possible associations between patients' health literacy (HL), psoriasis education, and knowledge have not yet been investigated, and the impact of HL on self-management needs to be illuminated further (18).

HL encompasses people's knowledge, motivation, and ability to access, understand, appraise and apply health information, and to make judgments and decisions about healthcare, disease prevention, and health promotion (19). Limited HL is associated with additional chronic conditions (20) increased hospitalization (21), poorer adherence to treatment (22), and lower educational attainment (23). Studies have also found that restricted HL indicates less communication with health care professionals (HCPs) (23,24) and lower self-management (25). Recently, HL as a more dynamic construct has been emphasized (26), where HL represents not only the skills needed by an individual to process health-related information but also develops from the interaction between patients and health care systems, organizations, and professionals (26).

Self-management approaches that incorporate peer support seem promising. Patients may learn better when they are taught by and provided self-management support from peers with whom they identify and share everyday experiences (27). Fellow patients may also provide positive role models for coping with psoriasis, as peer support combines the benefits of both receiving and providing social support (28). The literature is limited regarding the impact of peer support on psoriasis, but promising results regarding the value of peer support have emerged

from qualitative studies among adolescents (12,20). As such, research that evaluates HL with regards to education from HCPs, together with the experience of self-management and self-efficacy in patients with psoriasis, may increase our knowledge on how follow-up of these patients can be improved. Accordingly, the following research questions were posed:

- From which sources are patients receiving information on psoriasis? What is the patients' perceived importance of the information from these sources about living with psoriasis?
- Are there differences in HL, psoriasis knowledge, self-management and self-efficacy between patients reporting having received psoriasis education from HCPs compared to patients reporting not having received such education?
- To what extent is repeated participation in a multidisciplinary Climate Helio Therapy (CHT) program (thereby receiving more educational psoriasis training and additional interactions with health care providers and fellow patients) associated with HL, psoriasis knowledge, quality of life, and self-management?

Material and methods

Patients and methods

This study had a cross-sectional questionnaire design. In total, 1275 adults were included, all having participated in the Norwegian CHT program at least once from 2011 to 2017. CHT is one of the therapeutic options available to Norwegian patients with moderate to severe psoriasis. A 3-week multidisciplinary program is provided in Gran Canaria, which includes tailored sunlight UVB radiation (29,30), physical exercise, group discussions with peers, and comprehensive education. The study participants were invited by postal mail and sent the study information, consent form and survey questionnaire, including questions on health issues, experiences of education by HCPs, essential sources for psoriasis information and demographics. A reminder was mailed six weeks after the survey was distributed. Data collection took place from March to August 2017. A total of 825 patients completed and returned the questionnaire package (65% response rate).

Measures

Socio-demographic characteristics, e.g. age, gender, body mass index (BMI), education level, annual income, health condition, psoriasis duration, and additional diseases were obtained from the questionnaires.

The significance of 15 different informational sources (e.g. general practitioner [GP], nurse, dermatologist, the internet, and CHT) were measured with six different alternatives. Here, one option was 'Have not received information from this source' and the remaining options were then rated using a five-point scale, anchored on the left with the wording 'Very important' and the right with 'Not at all important.' These were further grouped into two categories: (1) 'Very or fairly important', and (2) 'Neither important nor unimportant' to 'Not important at all'.

The Health Literacy Questionnaire (HLQ; (31)) includes 44 items across nine independent scales, each representing a different element of the overall HL construct. Each scale containing four to six items. Scales 1–5 comprise items requesting that the respondents indicate their level of agreement, and the remaining scales (6–9) reflect self-reported capability. The full HLQ offers nine separate scores based on an average of the items within each of the nine scales, with higher scores indicating higher HL. The questionnaire has no total score, as that could potentially mask individual needs in specific HL domains (31) (Cronbach's alpha: 0.64 to 0.87).

Disease activity was measured by the Self-Administered Psoriasis Area and Severity Index (SAPASI; score: 0–72; higher score = more severe disease).

To measure self-management, two domains from the Health Education Impact Questionnaire (HeiQ), 'Skill and technique acquisition', and 'Self-monitoring and insight', were used. These items were rated on a Likert scale ranging from 'Strongly disagree' (1) to 'Strongly agree' (4). Higher scores indicate higher levels of self-management (32). (Cronbach's alpha was 0.76 for 'Self-monitoring and insight' and 0.82 for 'Skill and technique acquisition'.)

The 10-item Dermatology Life Quality Index (DLQI) measured the quality of life (QoL) on a scale from zero to 30 (33). Higher scores indicate more significant impairment of a patient's QoL (Cronbach's alpha: 0.90).

Psoriasis knowledge was measured by the Psoriasis Knowledge Questionnaire (PKQ), which contains 44 statements about psoriasis (11). A total score was calculated based on the number of correct answers, with a possible range from 0 to 44, where higher scores indicate higher levels of knowledge (Cronbach's alpha: 0.86).

Ethics

The study was approved by the Regional Committee for Medical Research Ethics for Southern Norway (ID 2016/1745) and conducted in accordance with the Helsinki Declaration. The administrative leaders of the Section for Climate Treatment at Oslo University Hospital and the Center for Privacy and Information Security at Oslo University Hospital also approved the study.

Statistics

All statistical analyses were performed using SPSS® version 25; p values $< .05$ were considered statistically significant. For all HLQ scales, assumptions of normal distribution were met. Chi-squared statistics were used to test for statistical significance in dichotomized variables; T-tests and Man–Whitney U-tests were used for differences between groups in normally- and not normally-distributed variables, respectively. The expectation maximization algorithm was used to impute missing HLQ item scores where there were fewer than two missing values from scales with four to five items and fewer than three missing values from the scale with six items (34). We dichotomized participants in two groups; the ones reporting having received psoriasis education from HCPs (in addition to education provided during CHT) and the ones reporting not having received such education. ANCOVA (SPSS general linear model) was used within a regression framework (with age, educational attainment and sex as covariates), with each of the domains of HLQ as the dependent variable to explore possible between-group differences. We also dichotomized participation in CHT treatment for people participating only once ($=0$), and those participating more than once ($=1$), using the same ANCOVA approach to explore differences in HL, self-management and knowledge. We report Cohen's d effect sizes or Hedges' g (groups unequal in size). The effect sizes were calculated for standardized differences (the differences between two means, divided by the pooled standard deviation [SD] of

both means). An effect size of 0.2 is considered a small effect, 0.5 indicates a moderate effect, and 0.8 is a substantial effect (35).

Results

Characteristics of the sample

In total, 435 men (52.7%) and 390 women (47.3%) participated in the study. The demographics and clinical variables are presented in Table 1, divided into educational groups. There were no between-group differences in demographic or clinical variables, except that those who received psoriasis education from HCPs were using significantly more biological treatments, had more comorbidities and a smaller percentage were working.

Sources of psoriasis information

The different sources of psoriasis information and their rated influence are presented in Figure 1. CHT (98%), fellow patients (81.2%), and the internet (78.8%) appeared to be the three most common information sources. The dermatologist at the

outpatient clinic was rated as 'very/fairly important' by 72.6% of respondents, peers by over 80%, and the CHT program by 98.4%. In comparison, information from GPs was rated as 'very/fairly important' by 42.6%.

Educational psoriasis training from HCPs

Table 2 presents the significance of education on psoriasis. In comparing the participants who reported having received additional education on psoriasis from HCPs (N = 433) with those who had not received such education (N = 363), the results showed that the latter group scored significantly lower in the nine HLQ scales indicating more HL limitations. [Cohen's effect size ranged from 0.24 (Actively managing health) to 0.44 (Active engagement with healthcare providers).]

The two HeiQ domains measuring self-management both showed significantly better self-management for the group that had received psoriasis education from HCPs, with a Cohen's effect size of 0.36 and 0.41. There was no significant between-group difference in DLQI or PKQ.

Table 1. Characteristics of participants.

	Full sample N = 825 N (%) mean (SD) Median (Range)	Not received psoriasis education by health care personnel (HCP) N = 438 N (%) mean (SD) Median (Range)	Received psoriasis education by HCP N = 367 N (%) mean (SD) Median (Range)	Between-group difference (95% confidence interval), p value (a, b, c)
Female sex	390 (47.3%)	213 (47.3%)	177 (47.2%)	X^2 = .001, p = .97 (b)
Male	435 (52.7%)	237 (52.7 %)	198 (52.8%)	
Age (years)	53.3 (12.4)	53.9 (11.70)	52.6 (13.11)	1.21 (−.44, 2.96), p = .15 (a)
Marital status:				X^2 = 2.58, p = .96 (b)
Married/cohabiting	544 (66 %)	300 (66.7%)	244 (65.2 %)	
Unmarried/single	128 (15.5 %)	66 (14.7 %)	62 (16.6 %)	
Divorced/separated/widowed	139 (16.9 %)	76 (16.9 %)	63 (16.9 %)	
Others	12 (1.4 %)	6 (1.3 %)	5 (1.3%)	
Level of education (N = 822)				X^2 = 0.72, p = .87 (b)
Primary/secondary school ≤ 10 years	94 (11.4%)	50 (11.2%)	44 (11.8%)	
Vocational/ High school ≤ 13 years	407 (49.3%)	218 (48.7%)	189 (50.5%)	
College/university < 3years	182 (22.1%)	104 (23.2%)	78 (20.9%)	
College/university ≥ 3years	139 (16.9%)	76 (17%)	63 (16.8%)	
Working	414 (50.6%)	247(55.4%)	167 (44.6 %)	X^2 = 8.93, **p= .003 (b)**
Not working	404 (49.4%)	199(44.9%)	205 (55.1%)	
Duration of disease in years	27 (077)	28 (0–77)	25 (0–65)	Z = −1.81, p = .071 (c)
Health condition (VAS scale 0–100)	60.11 (SD19.6)	60.62 (18.5)	59.5 (20.9)	1.12 (−1.60, 3.85), p = .42 (a)
Self-assessed health status (1–5 = poor– excellent)	3.33 (SD 0.92)	3.31 (0.91)	3.35 (0.93)	X^2 = −0.040 (−.17, .087), p = .54
Current smoker YES (n = 823)	194 (23.9%)	104 (53.6%)	90 (46.4%)	X^2 = 0.18, **p = .67 (b)**
Number of CHT treatment	2 (1–39)			
Biological medicines (N = 811) YES	115 (14.2%)	54 (46.2%)	63 (53.8%)	X^2 = 5.78, **p = .031 (b)**
Joint pain YES	551 (66.8%)	301 (54.6%)	250 (45.4%)	X^2 = .005, p = .94 (b)
Joint pain and PsA affirmed by rheumatologist YES	256 (46.5%)	136 (53.1%)	120 (46.9%)	X^2 = .121, p = .73 (b)
BMI	28.64 (5.30)	28.86 (5.13)	28.37 (5.49)	0.48 (−0.25, 1.22), p = .20 (a)
Number of comorbidities	4.4 (2.50)	4.20 (2.41)	4.62 (2.57)	−0.42 (−0.77, −0.07), **p = .018 (a)**
SAPASI (0–72, higher score = more serious disease)	7.51 (4.93)	7.30 (4.72)	7.77 (5.17)	−0.47 (−1.17, 0.23), p = .19 (a)
DLQI (0–30, higher score more impairment)	9 (0–30)	9 (0–27)	9 (0–30)	Z = −.40, p = .69 (c)
PKQ (0–44, higher score = more knowledge)	24.6 (7.26)	24.20 (7.27)	25.11 (7.21)	−0.92 (−1.91, 0.08), p = .072 (a)

BMI: Body Mass Index; DLQI: Dermatology Life Quality Index; PKQ: Psoriasis Knowledge Questionnaire; PsA: Psoriasis arthritis; SAPASI: Self-Administrated Psoriasis and Severity Index; SD: standard deviation.
Values are means (±SD) unless otherwise indicated. Difference between groups: (a) independent samples t-tests of means, (b) Pearson's Chi square (χ^2) tests of proportions and (c) Mann–Whitney U-tests of medians. N differs among individual analyses because of missing values. Bold values specify statistical significance (p < .05).
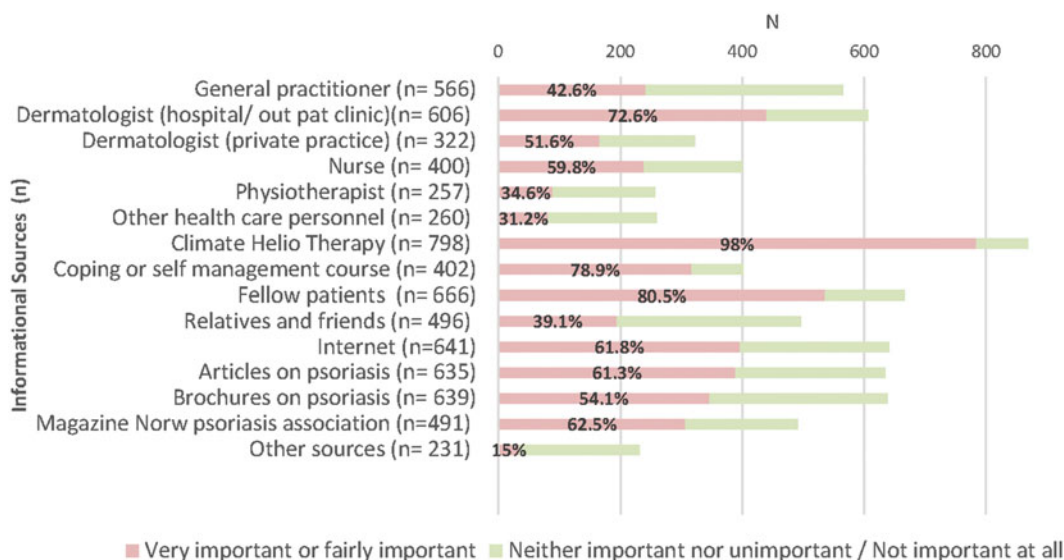
Figure 1. Frequency and percentage of importance of information from different sources (N = 809–815). The number answering 'yes' to having received psoriasis education is stated for each source (n).

Table 2. Difference in HLQ and HeiQ scores for participants having received education on psoriasis by Health Care Professionals and participants not receiving such education.

HLQ domains	Range	Not received psoriasis education dby HCP Mean (SD) N = 433	Received psoriasis education by HCP Mean (SD) N = 363	Mean difference, 95% confidence interval for difference, p value	Cohen's d effect size
(1) Feeling understood and supported by healthcare providers	1–4	2.59 (0.66)	2.87 (0.61)	.283, (.194,.373), **p < .001**	0.44
(2) Having sufficient information	1–4	2.57 (0.54)	2.73 (0.54)	.161, (.087,.236), **p < .001**	0.30
(3) Actively managing health	1–4	2.73 (0.51)	2.85 (0.51)	.126 (.056,.197), **p < .001**	0.24
(4) Social support	1–4	2.48 (0.60)	2.64 (0.60)	.165 (.982,.249), **p < .001**	0.27
(5) Critical appraisal	1–4	2.42 (0.51)	2.66 (0.55)	.238 (.164,.311), **p < .001**	0.45
(6) Active engagement with healthcare providers	1–5	3.25 (0.75)	3.56 (0.66)	.311 (.211,.410), **p < .001**	0.44
(7) Navigating the health care system	1–5	2.98 (0.73)	3.25 (0.66)	.287 (.189, .384) **p < .001**	0.39
(8) Ability to find good health information	1–5	3.32 (0.64)	3.49 (0.62)	.162 (.076, .248), **p < .001**	0.27
(9) Reading and understanding health information	1–5	3.51(0.62)	3.62 (0.61)	.113 (.028, .198), **p = .009**	0.18
HeiQ domains		N = 421	N = 353		
(1) Self-monitoring and insight	1–4	3.07 (0. 40)	3.24 (0. 43)	−.165 (−.223, −.106), **p = < .001**	−0.41
(2) Skill and technique acquisition	1–4	2.72 (0. 52)	2.91 (0. 53)	−.185 (.112, .259), **p = < .001**	−0.36
Quality of life		N = 424	N = 357		
Dermatology Quality of life Index (DLQI)	0–30	9.50 (6.69)	9.84 (7.30)	−.262, (−1.23, 0.71), p = .60	0.05
Knowledge		N = 441	N = 367		
Psoriasis Knowledge Questionnaire (PKQ)	0–44	24.26 (7.27)	25.24 (7.05)	−.906 (−1.83, 0.021), p = .055	0.14

HCP: Health care personnel; HLQ: Health Literacy Questionnaire (Range 1–4): 1 = Strongly disagree; 2 = Disagree; 3 = Agree; 4 = Strongly agree. (Range 1–5): 1 = Cannot do; 2 = Very difficult; 3 = Quite difficult; 4 = Quite easy; 5 = Very easy.
HeiQ: Health Education Impact Questionnaire. Significant differences were tested using analysis of variance (ANCOVA), with age, gender, number of climate therapy treatments, and educational level as covariates. Cohen's d expresses the effect size of each comparison. Bold values specify statistical significance (p < .05).

Differences in HL, self-management, and knowledge related to repeated CHT participation

Table 3 presents the difference in HL, self-management, and knowledge associated with CHT participation. Comparing the group who had participated once in CHT (N = 275) with those who had done so more than once (N = 509), we found that the latter group scored significantly higher in seven of the nine HLQ scales. (Hedges' g effect sizes ranged from 0.18 to 0.25.)

In the two HeiQ domains measuring self-management, we found a significantly higher score in the domain 'Skill and technique acquisition', favoring the more CHT-experienced patients [−0.137 (−0.216, −0.059), p = .001 (effect size 0.29)]. The PKQ

showed a remarkable difference favoring the same group, with an effect size of 0.75 (−5.08 [CI; −5.99, −4.16], p < .001).

Discussion

The main findings from this study indicate that psoriasis education by HCPs is associated with HL and psoriasis knowledge. The first research question was related to sources for information on psoriasis and the patients' perceived significance of such information. Despite the popularity of the internet, several patients reported the use of more traditional sources of information to be more important, particularly specialist care

Table 3. Differences in HLQ, HeiQ domains, quality of life, knowledge, and self-efficacy related to one or multiple participations in climate therapy.

HLQ domains	Range	Participated once in CHT Mean (SD) N = 275	Participated ≤ two times CHT Mean (SD) N = 509	Mean difference, 95% Confidence interval for difference, p value	Hedges' g effect size
(1) Feeling understood and supported by healthcare providers	1–4	2.61 (0.69)	2.76 (0.62)	−.143 (−. 239, −.048), **p = .003**	−0.23
(2) Having sufficient information	1–4	2.55 (0.56)	2.68 (0.53)	−.117 (−.196, −.038), **p = .004**	−0.24
(3) Actively managing health	1–4	2.75 (0.53)	2.80 (0.50)	−.049 (−.026, .124). p = .199	−0.10
(4) Social support	1–4	2.50 (0.65)	2.58 (0.57)	−.081 (−.170, .008), p = .07	−0.15
(5) Critical appraisal	1–4	2.46 (0.55)	2.57 (0.54)	−.112 (.033), .192), **p = .006**	−0.20
(6) Active engagement with healthcare providers	1–5	3.27 (0.76)	3.45 (0.70)	−.164 (−.271, −.057), **p = .003**	−0.25
(7) Navigating the health care system	1–5	3.00 (0.73)	3.15 (0.69)	−.137 (−.242, −.033), **p = .01**	−0.21
(8) Ability to find good health information	1–5	3.30 (0.63)	3.45 (0.63)	−.147 (−.238, −.057), **p = .001**	−0.24
(9) Reading and understanding health information	1–5	3.49 (0.64)	3.60 (0.62)	−.099 (−.189, −.009), **p = .030**	−0.18
HeiQ domains		N = 263	N = 498		
(1) Self-monitoring and insight	1–4	3.11 (0.43)	3.17 (0.41)	−.056 (−.120, .007), p = .081	−0.14
(2) Skill and technique acquisition	1–4	2.70 (0.55)	2.85 (0.51)	−.137 (−.216, −.059), **p = .001**	−0.29
Quality of life (DLQI)		N = 268	N = 498		
DLQI (0–30; higher score = more impairment)	0–30	9.96 (6.52)	9.48 (7.17)	.238 (−.785, 1.26), p = .65	0.07
Psoriasis Knowledge		N = 276	N = 517		
PKQ (0–44; higher score = more knowledge)	0–44	21.45 (7.00)	26.52 (6.61)	−5.08 (−5.99, −4.16), **p < .001**	0.75

CHT: Climate Helio Therapy; HLQ: Health Literacy Questionnaire (Range 1–4): 1 = Strongly disagree; 2 = Disagree; 3: Agree; 4 = Strongly agree. (Range 1–5): 1 = Cannot do; 2 = Very difficult; 3 = Quite difficult; 4 = Quite easy; 5 = Very easy. HeiQ: Health Education Impact Questionnaire (Range 1–4): 1 = Strongly disagree; 2 = Disagree; 3 = Agree; 4 = Strongly agree. DLQI: dermatology life quality index; PKQ: psoriasis knowledge questionnaire.
Significant differences were tested using analysis of variance (ANCOVA), with age, gender, and educational level as covariates. Hedges' g (unequal groups) expresses the effect size of each comparison. Bold values specify statistical significance (p < .05).

professionals, peers, and the CHT program. While this is in line with the results from a study on diabetes (36), some of our findings contrast those of other studies. A longitudinal study evaluating a cardiovascular risk reduction program (37) found that the patient-HCP relationship (primarily GPs) was important for HL. In an Italian study, the GP and the dermatologist were considered the best source for psoriasis information by the patients (38). In the present study, however, only 42.6% of the patients rated the information from their GPs as 'very/fairly important'.

Our results also show that many (54%) patients did not report having received psoriasis education from an HCP (other than the information obtained during CHT). It may, therefore, be essential to provide basic, tailored patient education more systematically for psoriasis, thus providing needed support from both HCPs and peers. There were no socioeconomic, nor clinical differences between those who received education and those who did not, except that the latter had a more severe comorbidity profile and more biological treatment. These differences, however, do indicate a more severe disease history, even if the SAPASI scores were almost identical at the time of our study (Table 1).

Research has also shown that HCPs have a limited understanding of HL and of their role in building HL skills (39). Moreover, HCPs' understanding of the barriers psoriasis patients face in developing these skills seems underexplored. The HCPs' barriers to practice e.g. lack of time and knowledge regarding effective ways to deliver information have been further underscored in several studies within psoriasis (2,40,41). These factors may further increase the gaps in knowledge and comprehension related to decision-making and self-management in psoriasis.

HL could be seen as a 'system issue', reflecting the complexity of the presentation of health information and navigation of the health care system (42). The findings from this study are in line with this perspective, as they show that patients with

psoriasis who perceive having received psoriasis education from an HCP scored significantly higher on all nine HLQ domains (Cohen's d: 0.18 to 0.45). The most substantial differences were in scales 1 (Feeling understood and supported by healthcare providers), 5 (Critical appraisal), and 6 (Active engagement with health care providers). In scale 1, a high score indicates that the respondent has established a trusting relationship with at least one HCP; in scale 6, it indicates that the respondent is proactive about their health and feels in control in their HCP relationships; and in scale 5, it indicates that the respondent is able to identify good and reliable sources of information and resolve conflicting information (31). All three scales reflect empowerment and collaborative, trusting relationships with HCPs. These results may, therefore, indicate that information and educational training provided by an HCP is positively related to HL and helps the patient to access and utilize health services effectively. Additionally, the HeiQ domains showed that the participants who had received education from an HCP also had higher self-management, related to both 'Self-monitoring and insight and Skill and technique acquisition'. Indeed, a systematic review of the impact of HL on self-management in chronic disease suggests that low HL may affect the behaviors necessary for the development of self-management skills (25).

The third research question focused on whether participants with repeated CHT participation scored differently than one-time participants. Ranges of potentially modifiable HL differences in the cohort were identified, indicating a beneficial effect of repeated participation. Here, there were smaller effect sizes, with the most substantial differences in scales 6 (Active engagement with health care providers), 2 (Having sufficient info …) and 8 (Ability to find good health information …). A high score in the latter two scales indicates that the patients are proactive about their health, feel in control in their relationships with HCPs (34), actively seek information, feel confident and can

make health-related decisions. Additionally, the 'Skill and technique acquisition' domain of self-management and psoriasis knowledge were significantly higher in patients who had participated repeatedly the effect size for the difference in psoriasis knowledge, in particular, was substantial.

A study exploring the development of HL in patients with long-term conditions (43) found that HL skills develop over time, as skills are put into practice: indeed, the patients became more active in health care consultations as their confidence and experience increased. These results may strengthen the notion that becoming health literate is an ongoing process that develops over time, through a range of health experiences and encounters within different health contexts (43), and that different health needs trigger HL development (44).

This seems congruent with our study findings, as repeated CHT participation means attaining increased psoriasis knowledge from recurring education and more interaction with both HCPs and peers. Our finding that CHT and peers were assessed as a vital source of information further supports this view. A thematic synthesis of qualitative studies on self-management support from the perspective of patients with a chronic condition also found that fellow patients are an important source of support, not only through sharing their lived experiences but also by fulfilling psychosocial needs (45).

In sum, psoriasis education seems important for both HL and for increasing patients` knowledge. People living with psoriasis may need multiple approaches and repetitions over time to become and remain health literate, and to be effective self-managers.

Strengths and limitations

A strength of this study is the use of the HLQ, a comprehensive measurement of HL encompassing a broad range of both resources and skills (31). Another strength is the relatively large sample size and high response rate (65%), given the mode of questionnaire distribution (via postal mail). However, some explanatory comments should be noted. Due to the cross-sectional design, conclusions about causality cannot be drawn. Another limitation concerns the use of a self-report questionnaire. Patients might not have been willing to report their poor HL and self-management behaviors honestly. As the written questionnaires were filled in at home, it is also possible that some patients received assistance completing the survey, or that we missed those patients with deficient literacy skills. A final limitation is a somewhat limited sample, as all participants experienced CHT and although their ages ranged from 18 to 84 years, most were middle-aged. This may reduce the generalizability of the results.

Future research and practice implications

Based on these results, especially the evident contribution of psoriasis education to HL, implementing psoriasis education and self-management support that is systematic and tailored may be beneficial. Such interventions should also be tested regarding their effectiveness in strengthening HL. Direct participation of patients in developing HL interventions and educational tools also seems necessary. Finally, a more comprehensive exploration of which factors in the relationship between HCPs and patients, and patients and peers, may facilitate and strengthen HL is needed.

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