

Could a handbook serve as a useful educational intervention in improving disease knowledge? A cross-sectional study among patients with hidradenitis suppurativa in Poland

Miłosz Lewandowski, Zuzanna Świerczewska, Wioletta Barańska-Rybak

Department of Dermatology, Venereology and Allergology, Faculty of Medicine, Medical University of Gdansk, Gdansk, Poland

Adv Dermatol Allergol 2022; XXXIX (6): 1157–1161

DOI: <https://doi.org/10.5114/ada.2022.117041>

Abstract

Introduction: Hidradenitis suppurativa (HS) is a chronic, recurrent inflammatory skin disease characterized by the occurrence of severe, painful nodules, abscesses, and fistulas, most commonly found in the skin folds of the axilla, groin, gluteal, and perianal areas. The disease is of interest to many researchers, however, verified information for patients is still limited.

Aim: To evaluate the baseline knowledge about acne inversa among patients suffering from the disease as well as to assess whether an educational intervention as a handbook can improve patients' knowledge of their illness.

Material and methods: This research study was a cross-sectional survey conducted on HS Facebook support group. The respondents completed an anonymized questionnaire assessing their state of knowledge about acne inversa. After 1 month they were presented with a handbook. Thereafter the patients completed nearly the same anonymized questionnaire assessing the state of knowledge after reading the handbook.

Results: We enrolled 102 participants before (group A) and 30 participants after (group B) the educational intervention. The vast majority of the participants (83.3%) appraised the idea of preparing a handbook as 10 points. In both groups, respondents who were aware of their disease severity had significantly superior results than the participants who were not. After reading the handbook extensively, more patients assessed the state of their general HS knowledge as 'good' than before.

Conclusions: Our study demonstrated that knowledge about HS among patients is still insufficient. Tools such as handbooks may prove useful in disseminating expertise and helping patients to understand their disease.

Key words: hidradenitis suppurativa, acne inversa, Facebook, handbook, education, intervention.

Introduction

Hidradenitis suppurativa (HS) is a chronic, progressive, debilitating, recurrent inflammatory skin disease characterized by the occurrence of very severe, persistent, painful nodules, abscesses, and fistulas, most commonly found in the skin folds of the axilla, groin, gluteal, and perianal areas [1]. There are several studies assessing the general prevalence of hidradenitis suppurativa. However, due to the demographic diversity of the surveyed populations and different research methodologies, the results of the studies differ significantly, and currently, the prevalence range

is estimated at 0.00033–4.1% [1, 2]. The incidence of the disease is the highest in the 20–40 age group. In the Caucasian population, it is also observed that the hidradenitis suppurativa occurs in women much more often than in men, with a ratio of 3 : 1 [2]. Being aware of the patients' needs and willingness to obtain reliable information about the disease, a handbook entitled "Hidradenitis suppurativa – a handbook for the patients", based on the current medical literature, was published in the 4th quarter of 2021 [3]. How patient education can affect health outcomes shows over 2000 times cited research about health literacy by Berkman *et al.* According to authors, low patients' health

Address for correspondence: Prof. Wioletta Barańska-Rybak, Department of Dermatology, Venereology and Allergology, Medical University of Gdansk, 17 Smoluchowskiego St, 80-214 Gdansk, Poland, phone: +48 58 584 40 10, fax: +48 58 584 40 20, e-mail: wioletta.baranska-rybak@gumed.edu.pl

Received: 1.05.2022, **accepted:** 10.05.2022.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International (CC BY-NC-SA 4.0). License (<http://creativecommons.org/licenses/by-nc-sa/4.0/>)

literacy is linked to disparities in the use of specific health-care services, such as greater hospitalizations, emergency room visits and also in health-related outcomes, including a lower capacity to show correct drug administration, worse interpretation of pharmaceutical labels and health messaging, as well as a lower overall health status and greater death rates among the elderly [4].

Aim

The aim of the study was to evaluate, using Facebook, the baseline knowledge about acne inversa among patients suffering from the disease as well as to assess whether an educational intervention as a handbook can improve patients’ knowledge of their illness.

Material and methods

This research study was a cross-sectional survey conducted on hidradenitis suppurativa Facebook support group, from 10 October 2021 until 30 December 2021. The only inclusion criteria of the study were the age > 18 years and diagnosis of HS. In the first step, the respondents completed a newly created anonymized questionnaire assessing their state of knowledge about acne inversa. After 1 month they were presented with a handbook, which they had the next 30 days to get acquainted with. Thereafter the patients completed nearly the same anonymized questionnaire assessing the state of knowledge after reading the handbook.

The questionnaire was unvalidated, self-created by the authors, and generated using Google® Forms. It comprised 14 single-choice and 3 multiple-choice questions assessing patients’ knowledge about the disease. In addition, the questionnaire included questions concerning the gender, age, educational level, demographic information, type of current treatment, Hurley stage of the disease, HS family history, and a few 10-point scale questions presented in Table 1. 10-point scale questions were divided and defined as follows: 1–3 poor, 4–7 moderate, and 8–10 good.

Statistical analysis

Completed surveys were downloaded for statistical analysis. The collected data were analysed in Statistica 13 software approaching χ^2 and Mann-Whitney tests. *P*-value equal to or less than 0.05 was considered statistically significant. Microsoft Excel 2019 was used for preparing tables. The study was approved by the Independent Bioethics Committee for Scientific Research at the Medical University of Gdansk (NKBBN/704/2021).

Results

We enrolled 102 participants before (named as group A) and 30 participants after (named as group B) the educational intervention.

Demographics of group A (before educational intervention)

Among this group, there was a significant difference in gender representation (87 women, 85.3%; 15 men, 14.7%). Almost the entire study, 102 respondents were in one of the three age groups (18–30 age group – *n* = 37, 36.3%; 31–40 age group – *n* = 31, 30.4%; 41–50 age group – *n* = 27, 26.5%). Almost a half (47.5%) of the respondents lived in the cities of more than 100,000 inhabitants, the rest 19.8%, 13.9%, and 18.8% in a town with 20,000 to 100,000 inhabitants, under 20,000 inhabitants, and in the countryside, respectively. Among participants, 57.8% had higher education, 38.2% secondary education, and only 4% primary education. Hurley stage of each patient’s disease is presented in Table 2.

Demographics of group B (after educational intervention)

Likewise in the first group, in group B there was also a significant difference in gender representation (27 women, 90%; 3 men, 10%). Nearly all respondents in this group pertained to one of the three age groups (18–30 age group – *n* = 9, 30%; 31–40 age group – *n* = 8, 26.7%; 41–50 age

Table 1. 10-point scale questions contained in questionnaires before and after educational intervention and additional 4 questions after educational intervention, respectively

10-point scale questions included in both questionnaires, before and after educational intervention questionnaire	Points
How do you rate your general knowledge about hidradenitis suppurativa?	1–10
How do you assess your knowledge of risk factors for hidradenitis suppurativa development?	1–10
How do you assess the state of your knowledge about comorbidities of hidradenitis suppurativa?	1–10
How do you rate your knowledge of the hidradenitis suppurativa treatment?	1–10
Additional 10-point scale questions included after educational intervention questionnaire	1–10
How do you rate the idea of preparing a handbook on hidradenitis suppurativa?	1–10
How do you rate the usefulness of the hidradenitis suppurativa handbook?	1–10
How do you rate the graphics of the handbook?	1–10
Did the handbook meet your expectations?	1–10

Table 2. Hurley stage of patient's disease

Hidradenitis suppurativa severity in Hurley Scale	Type of the group	
	Group A	Group B
Hurley stage I	19 (18.8%)	6 (20%)
Hurley stage II	31 (30.7%)	14 (46.7%)
Hurley stage III	17 (16.8%)	3 (10%)
Not aware of disease severity	34 (33.7%)	7 (23.3%)

group – $n = 9$, 30%). Correspondingly to the first group, a large proportion of respondents (56.7%) lived in the cities of more than 100,000 inhabitants, the rest 16.7%, 16.7%, and 10% in a town with 20,000 to 100,000 inhabitants, under 20,000 inhabitants, and in the countryside, respectively. Among this group, 55.2% had higher education, 37.9% secondary education, and 6.9% primary education. Hurley stage of each patient's disease is presented in Table 2.

Assessment of the handbook by patients

Respondents answered 4 questions rating on a scale of 1–10. The vast majority of the participants (25, 83.3%) appraised the idea of preparing a handbook as 10 points, another 10% as 8 points, only two of them rated it below 8 points, as 5 and 7 out of 10 points, respectively. Among the group, 46.7%, 13.3%, and 23.3% of respondents rated its usefulness as 10, 9, and 8 points, respectively. Nearly 70.1% of participants declared that the handbook met their expectations as greater than or equal to 8 points, while the graphic design was assessed as 'good' by 93% of respondents.

Patients' knowledge depending on the collected variables

There was only one significant statistical relationship between the assumed variables and the results of the 14 knowledge assessing single-choice questions. In both groups, those respondents who were aware of their disease severity (based on Hurley stage) had significantly superior results than the participants who were not ($p = 0.0069$ and $p = 0.0076$ respectively for people before and after educational intervention).

There were no significant correlations between gender, age, educational level, residence and the questionnaire results, in both research groups.

Comparison of the patients' knowledge before and after educational intervention

The mean score obtained by respondents in group B was substantially higher than in group A ($p = 0.000011$; $n = 30$, mean 10.4 points; $n = 102$, mean 7.91 points). The 30 patient group answered each question statistically better than 102 one, however for 5 out of 14 questions the difference was statistically significant. These questions with the p -value are presented in Table 3.

Table 3. Questions with the statistically significant difference between respondents before and after educational intervention

Questions (selectable answers)	P-value
Who suffers from acne inversa most often? (Women/Men/Children/I don't know)	0.026
May the obesity be a factor that exacerbates the course of the disease? (Yes/No/I don't know)	0.04
Do you think there are any medications that can help you fight the habit of smoking? (Yes/No/I don't know)	0.048
What is the name of an FDA registered biological drug for hidradenitis suppurativa treatment? (Dupilumab/Secukinumab (Cosentyx)/Adalimumab (Humira)/Bimekizumab/Etanercept (Enbrel)/Infliximab (Remsima))	0.0045
Can botulinum toxin (Botox) be used in the treatment of acne inversa? (Yes/No/I don't know)	< 0.00001

Improvement of patients' satisfaction after the educational intervention

After reading the handbook extensively, more patients assessed the state of their general HS knowledge as 'good' than before ($p < 0.00001$; $n = 22/30$, 73%; $n = 28/102$, 27%). The same applies to the patients' assessment of their knowledge of HS: risk factors, treatment, and comorbidities. The statistical summary of these questions is provided in Table 4.

Moreover, respondents, who assessed their knowledge as 'good' after reading the handbook had significantly higher questionnaire results than respondents who assessed their knowledge as 'good' before ($p = 0.026$; $n = 22/30$, 10.68; $n = 28/102$, 9).

Discussion

Despite the fact that hidradenitis suppurativa is increasingly diagnosed, it is still a rare condition. Acne inversa is of interest to many researchers and studies, however, easily accessible, verified information for patients is still limited.

We performed our study in response to numerous patients applying to our clinic, with the lack of hidradenitis suppurativa knowledge who had searched the Internet to obtain medical information. Because of its accessibility, Facebook is a highly popular social media platform with the potential to help decrease the health literacy gap [5]. Thus, practitioners from a variety of medical disciplines should be aware of opportunities offered by social media in providing information to their patients.

Educating patients about their disease is the subject of interest and discussion among many scientists of various medical specializations. To the best of our knowledge, only one research tried to bring up the problem and evaluate the state of patients' knowledge about hi-

Table 4. Patients' assessment on their knowledge of HS: general knowledge, risk factors, treatment, and comorbidities

Questions and assessment of patients on a scale of 1–10											P-value
Question	How do you rate your general knowledge about hidradenitis suppurativa? (1–3 poor, 4–7 moderate, 8–10 good)										
Points (1–10)	1	2	3	4	5	6	7	8	9	10	
Number of patients before intervention	2 (2%)	1 (1%)	5 (5%)	9 (8.9%)	17 (16.8%)	17 (16.8%)	22 (21.8%)	18 (17.8%)	6 (5.9%)	4 (4%)	< 0.00001
Number of patients after intervention	0 (–)	0 (–)	1 (3.3%)	0 (–)	4 (13.3%)	3 (10%)	0 (–)	7 (23.3%)	6 (20%)	9 (30%)	
Question	How do you assess your knowledge of risk factors of hidradenitis suppurativa development? (1–3 poor, 4–7 moderate, 8–10 good)										P-value
Points (1–10)	1	2	3	4	5	6	7	8	9	10	
Number of patients before intervention	7 (6.9%)	2 (2%)	11 (10.8%)	12 (11.8%)	17 (16.7%)	10 (9.8%)	15 (14.7%)	18 (17.6%)	4 (3.9%)	6 (5.9%)	< 0.00001
Number of patients after intervention	0 (–)	0 (–)	1 (3.3%)	0 (–)	3 (10%)	0 (–)	2 (6.7%)	10 (33.3%)	5 (16.7%)	9 (30%)	
Question	How do you assess the state of your knowledge about comorbidities of hidradenitis suppurativa? (1–3 poor, 4–7 moderate, 8–10 good)										P-value
Points (1–10)	1	2	3	4	5	6	7	8	9	10	
Number of patients before intervention	13 (12.7%)	9 (8.8%)	14 (13.7%)	9 (8.8%)	18 (17.6%)	8 (7.8%)	17 (16.7%)	10 (9.8%)	3 (2.9%)	1 (1%)	< 0.00001
Number of patients after intervention	0 (–)	0 (–)	1 (3.4%)	0 (–)	3 (10.3%)	1 (3.4%)	2 (6.9%)	8 (27.6%)	5 (17.2%)	9 (31%)	
Question	How do you rate your knowledge of the hidradenitis suppurativa treatment? (1–3 poor, 4–7 moderate, 8–10 good)										P-value
Points (1–10)	1	2	3	4	5	6	7	8	9	10	
Number of patients before intervention	4 (4%)	2 (2%)	8 (7.9%)	10 (9.9%)	9 (8.9%)	8 (7.9%)	24 (23.8%)	20 (19.8%)	12 (11.9%)	4 (4%)	0.0005
Number of patients after intervention	0 (–)	1 (3.4%)	1 (3.4%)	0 (–)	2 (6.9%)	3 (10.3%)	1 (3.4%)	7 (24.1%)	6 (20.7%)	8 (27.6%)	

dradenitis suppurativa [6]. In that study, the authors assessed the efficacy of patients' education on HS knowledge improvement by 45-minute lectures. As a result, all 20 patients reported that outcomes improved post-intervention. Also the ability to explain HS to another person and overall improvement in their knowledge of HS significantly improved. Compared to our research, the cited study did not investigate whether there was a relationship between the state of patient's knowledge and gender, age, educational level, or residence.

We believe that patient education can be an additional method to complement. There are several studies, not only associated with the field of dermatology, which described the significant influence of patient's education on the course of diseases, its severity, treatment efficacy, or quality of life (QoL). In the randomized controlled trial by Heratizadeh *et al.*, the educational training program among adults with atopic dermatitis (AD) shows beneficial effects on a variety of psychosocial parameters, as well as AD severity [7]. In another review study, which objective of

the article was to analyse and summarize evidence concerning the effects of patient education on QoL and disease severity in patients with chronic skin diseases, in five of 10 studies that met the inclusion criteria, statistically significant improvements in QoL were reported. Moreover, the severity of skin disease significantly improved in three studies [8]. However, slightly different results were shown in the meta-analysis, which determined the role of health education in HS treatment and its impact on outcomes in patients with chronic HS. The biggest impact of education was shown in terms of adherence to pharmacological therapy and self-care in that research, but education did not affect QoL [9]. A notable difference worth underlining is that the main educational tool used in the above-mentioned studies is educational programs, not the literature like books or handbooks, as it is in our research.

In our study, both groups mostly stated that smoking may worsen the severity of the disease, group A – 78.4%, group B – 90%, respectively. However, only 33.3% of patients before reading the handbook knew that there are some medications, which can help in smoking cessation. In this area we observed a statistically significant improvement, increasing the percentage of the correct answer to 53.3% among people after our educational intervention ($p = 0.048$). Currently, seven smoking cessation therapies are approved by the United States Food and Drug Administration (FDA), including two drugs: varenicline, bupropion [10]. As presented by Sabat *et al.*, lifestyle modification, including weight reduction and cessation of smoking, are crucial in HS management and the practitioners should present patients with possible therapeutic options that may help them in achieving their therapeutic goals [1].

High scores obtained from patients on questions about the idea of preparing the handbook, its usefulness, and meeting their expectations about it show that such educational tools may increase not only the patients' knowledge but also satisfaction with the treatment process. It has also been shown in two other studies. A systemic review by Dicipinigaitis *et al.* concluded that patient education neurosurgical programs in different forms, including text-based educational interventions, improve patients' awareness and satisfaction [11]. In the second study, a randomized controlled trial, authors concluded that written MRI materials before the examination not only reduce the probability of high anxiety levels before the scan but also increase patient satisfaction [12].

This study has some limitations. The most significant involve the difference in the size of the compared groups and the exclusion of patients under the age of 18 from our study. Considering the low prevalence of HS, the research group was also quite meagre. Furthermore, the research was based on an unvalidated questionnaire. Patients aged over 50, with a lower cultural level, and living in the countryside or towns under 20,000 inhabitants are less represented in the study.

Our study demonstrated that knowledge about HS among patients is still insufficient. It is crucial to promote reliable information about the disease as well as to educate patients, especially in the field of rare disorders. Tools such as handbooks may prove useful in disseminating expertise and helping patients to understand their disease. Moreover, it is worth underlining that Facebook may allow efficient and rapid distribution of such reliable medical knowledge. Further research is needed to investigate whether the educational tools in HS could be beneficial not only from the patient's point of view but may also be cost-effective, due to, *inter alia*, better mutual understanding and thus cooperation between the patients and the doctors.

Conflict of interest

The authors declare no conflict of interest.

References

1. Sabat R, Jemec GBE, Matusiak Ł, et al. Hidradenitis suppurativa. *Nat Rev Dis Primers* 2020; 6: 18.
2. Nguyen TV, Damiani G, Orenstein LAV, et al. Hidradenitis suppurativa: an update on epidemiology, phenotypes, diagnosis, pathogenesis, comorbidities and quality of life. *J Eur Acad Dermatol Venereol* 2021; 35: 50-61.
3. Barańska-Rybak W, Lewandowski M, Świerczewska Z. Trądzik Odwrócony: Poradnik Dla Pacjentów, „Gazeta GUMed”. Vol R.32. 1st ed.; 2022.
4. Berkman ND, Sheridan SL, Donahue KE, et al. Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med* 2011; 155: 97-107.
5. Whitaker C, Stevelink S, Fear N. The use of facebook in recruiting participants for health research purposes: a systematic review. *J Med Internet Res* 2017; 19: e290.
6. Prussick L, Tonelli S, Gottlieb AB, et al. Improving health literacy and treatment understanding of hidradenitis suppurativa using group educational interventions. *J Dermatolog Treat* 2019; 30: 708-13.
7. Heratizadeh A, Werfel T, Wollenberg A, et al. Effects of structured patient education in adults with atopic dermatitis: multicenter randomized controlled trial. *J Allergy Clin Immunol* 2017; 140: 845-53.e3.
8. de Bes J, Legierse CM, Prinsen CAC, de Korte J. Patient education in chronic skin diseases: a systematic review. *Acta Derm Venereol* 2011; 91: 12-7.
9. Alicja Świątoniowska-Lonc N. Cite as the Creative Commons Attribution 3.0 Unported (CC BY 3.0) Address for correspondence Funding sources. *Adv Clin Exp Med* 2020; 29: 481-92.
10. Smith LC, George O. Advances in smoking cessation pharmacotherapy: non-nicotinic approaches in animal models. *Neuropharmacology* 2020; 178: 108225.
11. Dicipinigaitis AJ, Li B, Ogulnick J, et al. Evaluating the impact of neurosurgical educational interventions on patient knowledge and satisfaction: a systematic review of the literature. *World Neurosurg* 2021; 147: 70-8.
12. Bolejko A, Hagell P. Effects of an information booklet on patient anxiety and satisfaction with information in magnetic resonance imaging: A randomized, single-blind, placebo-controlled trial. *Radiography* 2021; 27: 162-7.