e-HEALTH LITERACY IN ADULTS WITH HIDRADENITIS SUPPURATIVA (HS): A WORLDWIDE STUDY IN 20 COUNTRIES TO EXPLORE ASSOCIATED FACTORS

B. Halioua¹, C. Le Roux-Villet², M. Saint Aroman³, Y. Ben Hayoun⁴, C. Taieb⁵, M.-F. Bru⁶, C. Baissac³, C. Skayem^{7, 8}, M.-A. Richard^{9, 10}

¹ Centre de dermatologie, Paris, France ² Dermatologie, Hôpital Avicenne AP-HP, Centre de référence MALIBUL, Groupe Bulles de la SFD, Bobigny, France ³ Pierre Fabre, Patient centricity, Toulouse, France ⁴ EMMA, Data Scientist, Tel Aviv, Israël ⁵ EMMA, Patients priority, Paris, France ⁶ Association Française pour la Recherche sur l'Hidrosadénite, Patient Expert, Ile de la Réunion, France ⁷ Sorbonne University, Faculty of medecine, Paris, France ⁸ Hôpitaux de Paris (AP-HP), Hôpital Ambroise Paré, Department of Dermatology, Boulogne Billancourt, France ⁹ Assistance Publique des Hôpitaux de Marseille, Aix Marseille University, Department of Dermatology, Marseille, France ¹⁰ Société Française de Dermatologie, HS France, Paris, France



Disclosure Information:

Abbvie,
UCB,
Leo Pharma,
Lilly,
Novartis,
Almirall,
Pierre Fabre,
La Roche Posay

Commercial Support Information:

As part of the ALL [All Skins, All colors, All dermatoses] project, this work was funded by Patient Centricity by Pierre Fabre, France





Introduction

- Social media has become a modality for patient education, misinformation, and marketing in dermatology
- The concept of eHealth literacy is introduced and defined as the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem ⁽¹⁾.
- HL influences both well-being and health⁽²⁾
- Lower HL has been linked with poorer health outcomes (meaning less successful treatment) (3)
- Data on HL in people with Hidradenitis suppurativa (HS) is lacking.
- The main objective of this study was to assess HL in patients with hidradenitis suppurativa (HS) and to explore factors associated with eHealth literacy.

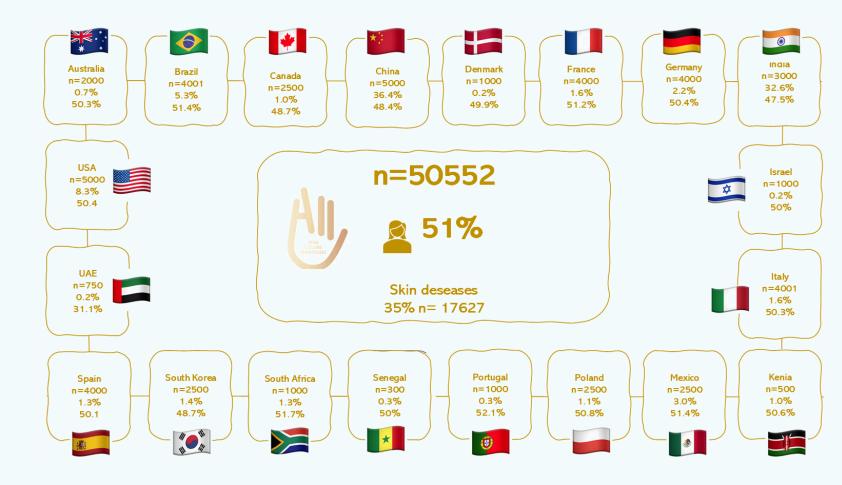
 | Open the main objective of this study was to assess HL in patients with hidradenitis suppurativa (HS) and to explore factors associated with eHealth literacy.
 - 2) Nutbeam D. Annu Rev Public Health. 2021 Apr 1:42:159-173
 - 3) Ishikawa H,. Health Expect. 2008 Jun;11(2):113-22

Material and methods

20 COUNTRIES FOR OVER 50% OF THE WORLD'S POPULATION!

Online survey of the general population over 16 years of age in 20 countries worldwide.

- Demographic and socio-demographic profiles
- Optional report ethnic and racial origin
- Self-reported Fitzpatrick skin phototypes
- Presence of a dermatological condition occurring in the past year



Material and methods

- Hidradenitis suppurativa reported by the patients on the basis of a diagnosis by a doctor
- Patients who stated using the internet to find reliable information about their skin problems were used to assess eHealth literacy (eHI)
- Socio-demographic and clinical characteristics
- Type of treatment
- Fear of adverse effects
- Feelings of discouragement to continue treatment
- Satisfaction with the treating physician.



586 HS respondents :

302 (51.5%) males (mean age 36+/-11.6). min 16-82 years).

- 371 patients (63.3%) had used the Internet to obtain information about their disease.
- =>187 (50.4%) specialist websites
- =>156 (42.0%) Pharmaceutical-supported websites
- => 172 (46.4%) discussion forums
- =>158 (42.6%) blogs or influencers.



n=27175 Males 14674 (54%) / Females 12591 (46%) Mean age 44.7 +/-15.7 yrs



HS n=586 302 (51.5%) males (mean age 36+/-11.6). min 16-82 years

When you're looking for reliable information about your skin problems, who do you turn to?

Specialised websites 187 (50.4%) Pharmaceuticalwebsites 156 (42.0%)

Discussion forums 172 (46.4%) Blogs or influencers. 158 (42.6%)



371 (63.3%) HS had used the Internet to obtain information about their disease.

Results

• Socio-demographical characteristics of HS with eHI:

- =>Female gender (52% vs. 42.3%, p \leq 0.05)
- => Age no Mean age (35.5 vs 36.9 years, NS),.
- => Professional activity (59.6% vs. 51.2%, $p \le 0.05$)

Burden of HS with eHI

- => Embarrassment in personal life (90% vs. 76.7%, p \leq 0.05)
- => Embarrassment in professional life (82.2% vs. 72.1%, p \leq 0.05).

Feeling of stigmatisation of HS with eHI

- =>Feeling left out or rejected by others (60.1%vs 53%, p \leq 0.05)
- => Feeling looked at with disgust (67%vs 48.4%, $p \le 0.05$)
- => Feeling that you avoid touching them (67.5% vs 47%, p \leq 0.05)
- => Feeling that you avoid approaching them (59%vs 44.2%, $p \le 0.05$)

Type of medical care of patients with eHI

Consultation of HS

- => Satisfaction with explanations given by physicians was lower in eHi (26.3% vs. 31.9%, $p \le 0.05$)
- =>Duration of the consultation (22.9% vs. 38.5%, NS) and satisfaction with the doctor's care (25.6% vs. 34.1%, NS) were not significantly lower in eHi.

Treatment of HS

- => Receiving injectable treatments (42.3% vs 24.2%, p ≤ 0.05)
- => Having worries about side effects (72.6% vs 58.3%, p ≤ 0.05)
- => Feeling discouraged about continuing treatment (74.1% vs 58.3%, p ≤ 0.05)

Conclusion

- First study of eHealth literacy in patients with HS
- The access of adults with HS to online resources may have a major impact on their health behaviours and outcomes.
- Healthcare providers should assess eHealth literacy of HS patients and direct them to appropriate and reliable online resources.
- The development of interventions to improve eHealth literacy and/or usability of web-based information for adults with HS is essential.
- More research is needed to implement/construct programmes/interventions promoting concerning knowledge on eHealth literacy literacy