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Tomasz Skrzypczak

Holistyczna analiza poziomu czytelności ogólnodostępnych artykułów on-line dotyczących wybranych schorzeń dermatologicznych

ROZPRAWA DOKTORSKA

Cykl publikacji powiązanych tematycznie

PROMOTOR:

Prof. dr hab. n. med. dr h.c. Jacek Szepietowski

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Pragnę złożyć najszczersze podziękowania mojemu promotorowi,

Panu ***prof. dr. hab. n. med. dr. h.c. Jackowi Szepietowskiemu****, Kierownikowi Katedry i Kliniki Dermatologii, Wenerologii i Alergologii Uniwersytetu Medycznego im. Piastów Śląskich we Wrocławiu*

za wsparcie, zawsze otwarte drzwi gabinetu, niespotykaną przychylność i wyrozumiałość, każdą uwagę i bezcenną pomoc, bez której nie byłoby możliwe powstanie tej pracy.

Rodzicom i przyjaciołom

Spis treści

1. CYKL PRAC STANOWIACYCH ROZPRAWĘ DOKTORSKĄ

1. **Skrzypczak T**, Skrzypczak A, Szepietowski JC.: Readability of Patient Electronic Materials for Atopic Dermatitis in 23 Languages: Analysis and Implications for Dermatologists. Dermatol Ther (Heidelb). 2024;14(3):671-684
   doi: 10.1007/s13555-024-01115-1.

   Impact Factor: 3,4
   Punktacja Ministerialna: 100

2. **Skrzypczak T**, Skrzypczak A, Szepietowski JC.: Hidradenitis Suppurativa Online Documents Readability: An Analysis Including 23 European Languages. Clin Cosmet Investig Dermatol. 2024;17:853-862
   https://doi.org/10.2147/CCID.S463861

   Impact Factor: 2,3
   Punktacja Ministerialna: 100

3. **Skrzypczak T**, Skrzypczak A, Szepietowski JC.: Deciphering the enigma of itch sensation: insights and impact from a readability study. Int J Dermatol. 2024 Apr 5. ahead of print
   doi: 10.1111/ijd.17144.

   Impact Factor: 3,6
   Punktacja Ministerialna: 70

Sumaryczny Impact Factor: ***9,3***
Sumaryczna Punktacja Ministerialna: ***270 punktów***

2. WYKAZ SKRÓTÓW

AZS	Atopowe zapalenie skóry
HS	Trądzik odwrócony (ang. hidradenitis suppurativa)
LIX	Wskaźnik czytelności (swe. läsbarhetsindex)
UE	Unia Europejska
GT	Tłumacz Google (ang. Google Translate)
RLF	Filtr języka wyników (ang. Results Language Filter)
MNiSW	Ministerstwo Nauki i Szkolnictwa Wyższego
IF	Współczynnik wpływu (ang. Impact Factor)

3. OMÓWIENIE ROZPRAWY DOKTORSKIEJ

3.1 Wstęp

Świąd towarzyszy dużej grupie pacjentów z chorobami skóry, przy czym często jest on przewlekły. Uciążliwe i nieprzyjemne uczucie świądu skłania chorych do szukania pomocy w każdym możliwym miejscu, w tym w Internecie. Podkreśla to znaczenie łatwo dostępnej i zrozumiałej dla pacjentów informacji zdrowotnej. Zasoby internetowe pełnią kluczową rolę jako źródło informacji dla pacjentów cierpiących na różne choroby skóry, w tym atopowe zapalenie skóry (AZS) i hidradenitis suppurativa (HS). AZS charakteryzuje się zapalnymi i swędzącymi wykwitami skórnymi, które znacznie upośledzają codzienne funkcjonowanie i wpływają na obniżenie jakości życia pacjentów. Pomimo znacznych postępów w zrozumieniu patogenezy AZS i wprowadzeniu nowych możliwości terapeutycznych, dużym wyzwaniem nadal pozostaje słabe przestrzeganie zaleceń lekarskich. Terapia AZS wiąże się z systematyczną i prawidłową pielęgnacją skóry. Nie jest ona możliwa bez odpowiedniego przeszkolenia i współpracy pacjenta. Podkreśla to potrzebę edukacji pacjentów oraz dostępu do zrozumiałej informacji dotyczącej pielęgnacji schorowanej skóry. Podobnie HS, przewlekła choroba zapalna skóry, która jest wyzwaniem diagnostycznym i terapeutycznym skłania pacjentów do szukania informacji w Internecie. Objawy skórne HS manifestują się często w miejscach intymnych. W obawie przed wstydem pacjenci unikają wizyt i badania lekarskiego. Próbują samodzielnie zdiagnozować się z pomocą dostępnych im źródeł, w tym Internetu. HS sprawia duże trudności diagnostyczne również lekarzom, którzy nie są dermatologami. Nie można wykluczyć faktu, że praktykujący lekarze innych specjalności sami starają się uzupełnić swoją wiedzę ogólnodostępnymi materiałami poszukując trafnej diagnozy dla pacjentów z HS w Intrenecie. Czytelność ogólnodostępnych artykułów internetowych poświęconych AZS i HS pozostaje mało zbadana. Dane dotyczące języków europejskich są bardzo ograniczone. Znamiennym jest również fakt samokształcenia się pacjentów przed wizytą lekarską. Internet stał się wiodącym źródłem wiedzy w ostatnich latach. Ogólnodostępne materiały online potrafią wykreować nierealistyczne oczekiwania pacjenta wobec spodziewanego efektu terapeutycznego jak i umniejszyć wagę potencjalnych działań niepożądanych. Jest to szczególnie ważne w aspekcie coraz liczniej wkraczających do praktyki klinicznej leków biologicznych i małych cząsteczek. Podkreśla to potrzebę zbadania czytelności ogólnodostępnych artykułów internetowych poświęconych schorzeniom dermatologicznym.

3.2 Cel badań i problemy badawcze

Celem badań wchodzących w skład rozprawy doktorskiej była analiza czytelności ogólnodostępnych materiałów online dedykowanych świądowi, świerzbiączce, AZS i HS przy pomocy wskaźnika czytelności läsbarhetsindex (LIX), z uwzględnieniem artykułów w oficjalnych językach krajów Unii Europejskiej (UE) oraz analiza zależności między liczbą potencjalnie dostępnych artykułów a ich czytelnością.

Cele szczegółowe:

3.2.1 Ocena czytelności ogólnodostępnych artykułów online opisujących świąd, świerzbiączkę, AZS i HS, w językach krajów UE

3.2.2 Analiza zależności pomiędzy językiem i źródłem artykułu a jego czytelnością

3.2.3 Porównanie otrzymanych wskaźników ze statystykami dotyczącymi wykształcenia w krajach UE celem oceny proporcjonalności czytelności informacji dostępnej online

3.2.4 Zbadanie korelacji pomiędzy liczbą potencjalnie dostępnych materiałów a ich czytelnością

3.3 Materiał i metody

Wszystkie trzy artykułu z cyklu były oparte na podobnej metodologii. Słowo lub słowa klucze były tłumaczone na wybrane języki krajów UE. Każde tłumaczenie było szukaną frazą w nowej sesji wyszukiwarki Google (GS). Każda sesja była otwierana w prywatnej karcie przeglądarki, a preferowany język usług wyszukiwania był taki sam jak język szukanego hasła. Domyślnie stosowany był filtr języka wyników (RLF), aby wykluczyć strony internetowe w innych językach z generowanej listy wyników. Metodologia ta była zgodna z rekomendacjami firmy Google (Google LLC, Mountain View, Kalifornia) dla wyszukiwania w językach obcych. W pierwszych dwóch pracach z cyklu słowa klucze były tłumaczone na dwadzieścia trzy oficjalne języki UE: bułgarski, chorwacki, czeski, duński, niderlandzki, angielski, estoński, fiński, francuski, niemiecki, grecki, węgierski, irlandzki, włoski, łotewski, litewski, polski, portugalski, rumuński, słowacki, słoweński, hiszpański i szwedzki. Z uwagi na fakt, że wyszukiwarka Google nie obsługuje języka maltańskiego jako preferowanego języka usług, ten dwudziesty czwarty oficjalny język UE nie został uwzględniony w badaniach. W pierwszej pracy z cyklu szukanym słowem kluczem było „atopic dermatitis" a w drugiej były „hidradenitis suppurativa" i „acne inversa". W trzeciej pracy z cyklu użyte zostały dwie grupy szukanych słów kluczy. W grupie *itch* znajdowały się słowa klucze „itch" i „pruritus". W grupie *prurigo* były „prurigo", „prurigo nodularis" i „chronic prurigo". Wszystkie zostały przetłumaczone na pięć najbardziej powszechnych języków krajów UE: angielski, niemiecki, włoski, francuski oraz hiszpański. W pierwszej pracy z cyklu tłumaczenia były uzyskiwane przy pomocy usługi Tłumacza Google (Google LLC, Mountain View, Kalifornia) (GT). W drugiej pracy i trzeciej pracy z cyklu, tłumaczeń słów kluczy szukano w artykułach wirtualnej encyklopedii Wikipedii (Wikimedia Foundation, https://www.wikipedia.org) napisanych w danym języku, gdy tłumaczenie uzyskane przy pomocy GT nie było dostępne lub wystarczająco wiarygodne.

We wszystkich trzech pracach z cyklu, każdy z 50 pierwszych wyników listy wygenerowanej podczas każdej sesji wyszukiwania był oceniany pod kątem stosowności. Artykuły dostępne bez opłat, bez konieczności założenia konta na stronie internetowej, mające głównie charakter edukacyjny były włączone do analiz. Materiały, które były w innym języku niż wyszukiwana fraza, chronione hasłem lub kontem dostępu były wykluczone z badań. Dodatkowo wszystkie artykuły naukowe, widea, blogi osobiste, fora online i reklamy nie były włączane do analiz. Strona internetowa była klasyfikowana jako reklama, gdy w głównej mierze zawierała artykuły promujące określony lek, praktykę lekarską, lekarza i/lub nie miała

wartości edukacyjnej. Również artykuły dedykowane profesjonalistom z branży medycznej, lekarzom, wydane przez organy regulacyjne lub odnoszące się do medycyny weterynaryjnej i/lub medycyny alternatywnej były wykluczane z analizy. We wszystkich trzech pracach z cyklu zdublowane artykuły nie były uwzględniane w badaniach. Dla każdego tłumaczenia zapisywana była liczba wyszukanych materiałów włączonych do badań oraz liczba trafień (ang. number of hits), która odzwierciedla liczbę potencjalnie dostępnych materiałów pod wyszukiwaną frazą. W drugiej i trzeciej pracy z cyklu, gdy różne szukane frazy prowadziły do tych samych artykułów, powielone materiały nie były uwzględniane w badaniach.

W pierwszej i drugiej pracy z cyklu artykuły były dodatkowo kategoryzowane ze względu na ich źródło. Źródło artykułu było klasyfikowane jako non profit, jeśli spełnił on co najmniej jedno z następujących wymagań: 1) został wydany przez szpital, przychodnię lub praktykę, której nadrzędnym celem nie było generowanie zysku; 2) został opublikowany przez organizację non profit, zajmującą się pomocą chorym na AZS w przypadku pracy pierwszej lub HS w przypadku drugiej pracy z cyklu; 3) został opublikowany na stronie internetowej, której głównym celem nie było zachęcenie czytelnika do zarezerwowania konsultacji lekarskiej czy kupna określonego leku, testu laboratoryjnego i/lub innych dóbr. Źródło materiału było klasyfikowane jako sklep internetowy, gdy strona internetowa oferowała możliwość zakupu leków, badań laboratoryjnych, recept czy konsultacji lekarskich, ale nie została sklasyfikowana jako reklama. Źródła artykułów wydanych przez firmy zajmujące się wytwarzaniem leków, były klasyfikowane jako firmy farmaceutyczne. Artykuły te nie były sklasyfikowane jako reklamy, miały wyraźnie edukacyjny charakter, jednak obecność nazw firmowych, znaków towarowych i wyskakujących reklam, wskazywały na ich nastawienie na zysk. Jeśli strony te oferowały możliwość kupna jakichkolwiek dóbr, ich źródło było klasyfikowane jako sklep internetowy. Klinika dermatologiczna była kategorią źródła dla artykułów, które były wydane przez praktykę lekarską, przychodnię lub szpital. Nie reklamowały one żadnego konkretnego lekarza, leczenia czy placówki medycznej, jednak nie można było wykluczyć ich nastawienia na zysk. Strony te zawierały informacje niezbędne do umówienia wizyty takie jak adres, telefon czy email. Również, gdy strony te oferowały możliwość zakupu jakichkolwiek dóbr, ich źródła były klasyfikowane jako sklep internetowy.

We wszystkich trzech pracach z cyklu czytelność artykułów była oceniania przy pomocy wskaźnika czytelności LIX. Jest to zweryfikowany instrument oceny czytelności, którego rzetelność została udowodniona dla wielu języków europejskich, w tym szwedzkiego, duńskiego, angielskiego, francuskiego, niemieckiego, fińskiego, włoskiego, hiszpańskiego i

portugalskiego. Jest on uznawany przez społeczność naukową za rzetelną miarę czytelności dla wszystkich języków europejskich. Poza byciem łatwym w liczeniu i interpretacji, omija on problemy z sylabizacją, co czyni go odpowiednim nawet dla tak skomplikowanych języków jak chiński i arabski. Tekst każdego analizowanego materiału był przekopiowywany do oddzielnego pliku tekstowego Microsoft Word (Redmond, USA). Wszystkie zbędne elementy artykułu takie jak afiliacje, hiper – linki, ryciny, legendy, oświadczenia, reklamy, informacje o autorach i prawach autorskich były usuwane. W tym celu używana była funkcja „Zachowaj tylko tekst". Program Microsoft Word był używany do sprawdzenia i korekty błędów w pisowni i gramatyce, poprzez wybór odpowiedniego języka dla tekstu. Każdy artykuł był przechowywany jako osobny plik, a tekst był przekopiowywany do kalkulatora wskaźnika LIX na stronie internetowej https://haubergs.com/rix . Zapisywana była całkowita liczba zdań, słów, średnia liczba słów w zdaniu wraz z wynikiem LIX. Tekst z wynikiem <20 był klasyfikowany jako bardzo łatwy do zrozumienia, < 30 jako łatwy, < 40 jako lekko trudny, < 50 jako trudny i < 60 jako bardzo trudny do pojęcia.

Do analizy statystycznej wykorzystano oprogramowanie JASP w wersji 16.59 (JASP Team, University of Amsterdam). Programy Microsoft Word i Microsoft Excel (Redmond, USA) w wersji 16.59 były użyte do agregacji danych. Wszystkie dane zostały przedstawione jako średnia ± odchylenie standardowe. $P < 0.05$ uznawane było za statystycznie istotne.

3.4 Podsumowanie wyników

W całym cyklu prac przeanalizowano łącznie 1387 artykułów, z czego 615 było poświęcone AZS, 458 HS a 314 artykułów odnosiło się do świądu i świerzbiączki. Pojęcie „hidradenitis suppurativa" i jego tłumaczenia były dużo bardziej popularne w nienaukowej literaturze niż określenie „acne inversa". Do badań zakwalifikowanych zostało 306 artykułów wyszukanych przy pomoc słowa klucz „hidradenitis suppurativa" i 152 materiałów z użyciem „acne inversa". Grupa 314 artykułów zawierała 205 pozycji znalezionych przy pomocy grupy słów kluczy *itch* oraz 109 pozycji znalezionych przy pomocy grupy słów kluczy *prurigo*. Tłumaczenia słowa „itch" w języku włoskim i francuskim były bardzo zbliżone do składni tłumaczenia słowa „pruritus". Artykuły wyszukane przy pomocy tych tłumaczeń były włączane do grupy artykułów wyszukanych przy pomocy słowa „pruritus". W rezultacie „pruritus", wraz ze 142 artykułami był najliczniej występującym określeniem w grupie *itch*. W grupie *prurigo* tylko 9 artykułów zostało wyszukanych przy pomocy „chronic prurigo". Były one najmniej liczne spośród całej grupy *prurigo*. Najczęściej występującym określeniem w grupie *prurigo* było „prurigo nodularis", przy pomocy którego włączono do badania 84 artykuły. Zaledwie 16 artykułów było znalezionych przy pomocy słowa „prurigo".

Ogólna wartość wskaźnika LIX artykułów poświęconych AZS wynosiła 56 ± 8, dedykowanych HS 57 ± 9, opisujących świąd i świerzbiączkę 54 ± 9. Wartości te klasyfikują analizowane artykuły we wszystkich pracach z cyklu jako bardzo trudne do zrozumienia. Nie było statystycznie istotnej różnicy wartości wskaźnika LIX pomiędzy artykułami znalezionymi przy pomocy „hidradenitis suppurativa" i „acne inversa". Artykuły z grupy *itch* miały znacząco niższą wartość wskaźnika LIX, 52 ± 9 w porównaniu do artykułów z grupy *prurigo*, 56 ± 10 ($P < 0.001$). Wskaźnik LIX dla artykułów znalezionych z użyciem słowa „itch", 49 ± 7 był znacząco niższy niż dla tych znalezionych przy pomocy słowa „pruritus", 54 ± 9 ($P < 0.001$). W grupie *prurigo* artykuły zebrane przy pomocy „chronic prurigo" miały najwyższy wskaźnik LIX, 64 ± 8, podczas gdy te wyszukane przy pomocy „prurigo nodularis" miały najniższy, 55 ± 10 ($P = 0.021$).

Artykuły napisane w języku angielskim, niderlandzkim i szwedzkim miały najniższe wartości wskaźnika LIX i były najłatwiejsze do zrozumienia. W pierwszej pracy z cyklu (AZS) wynosiły odpowiednio 42 ± 6, 47 ± 5, 47 ± 7, w drugiej (HS) 48 ± 10, 49 ± 5 i 49±5. W trzeciej pracy (itch/pruritus i prurigo) z cyklu wskaźnik LIX dla języka angielskiego wynosił 47 ± 10. Artykuły napisane w tych językach jako jedyne zostały sklasyfikowane jako trudne do zrozumienia. Wartości wskaźnika LIX dla analizowanych artykułów napisanych w pozostałych

językach przekraczały wartość 50 punktów, co klasyfikowało je jako bardzo trudne do zrozumienia. Najtrudniejsze do zrozumienia były artykuły napisane w języku fińskim i węgierskim. W pierwszej pracy z cyklu (AZS) średnie wartości wskaźnika LIX wynosiły odpowiednio 68 ± 6 i 65 ± 5, a w drugiej (HS) 68 ± 9 i 64 ± 12. We wszystkich trzech pracach z cyklu różnice wartości wskaźnika LIX pomiędzy uwzględnionymi językami były statystycznie istotne, wszystkie $P < 0.001$.

W pierwszej i drugiej pracy z cyklu analizowana była zależność pomiędzy źródłem artykułu a jego czytelnością. Artykuły dotyczące AZS wydane przez organizację non-profit i firmy farmaceutyczne były najbardziej zrozumiałe. Dla artykułów wydanych przez organizacje non-profit wskaźnik LIX wynosił 56 ± 9, przez kliniki dermatologiczne 59 ± 8, przez sklepy internetowe 58 ± 7 i 56 ± 8 dla artykułów wydanych przez firmy farmaceutyczne (P <0.001). Pomimo różnych wartości wskaźnika LIX dla wszystkich kategorii źródeł, każde z nich wydało artykuły sklasyfikowane jako bardzo trudne do zrozumienia. W drugiej pracy z cyklu nie znaleziono istotnych statystycznie różnic wartości wskaźnika LIX pomiędzy kategoriami źródeł.

Ogólny średni wynik wskaźnika LIX artykułów dotyczących AZS w pierwszej pracy z cyklu wynosił 56 ± 8. W drugiej pracy z cyklu dla artykułów poświęconych HS wynosił on 57 ± 9. Uzyskane wskaźniki czytelności odpowiadały poziomowi uniwersyteckiemu. W UE, tylko 32% populacji ukończyło studia wyższe. Artykuły poświęcone AZS i HS były zrozumiałe tylko dla jednego z trzech potencjalnych pacjentów. Artykuły poświęcone świądowi i świerzbiączce miały ogólną wartość wskaźnika LIX 54 ± 9. Wartość ta odpowiadała poziomowi szkoły średniej. W UE około 84% mieszkańców ukończyło co najmniej szkołę średnią. Oznacza to, że artykuły o świądzie i świerzbiączce były zrozumiałe dla większości populacji UE.

W pierwszej pracy z cyklu, zaobserwowana została słaba korelacja pomiędzy czytelnością materiałów poświęconych AZS a liczbą trafień, która odzwierciedla liczbę potencjalnie dostępnych materiałów (R^2 = 0.189, P = 0.031). Duża liczba potencjalnie dostępnych materiałów była skorelowana z ich niską czytelnością. W drugiej i trzeciej pracy z cyklu, nie zostały znalezione istotnie statystycznie korelacje pomiędzy czytelnością artykułów poświęconych HS, świądowi i świerzbiączce a liczbą trafień.

3.5 Etyka

Praca doktorska oparta na wyżej wymienionych publikacjach nie wymagała opinii Komisji Bioetycznej. W przeprowadzonych badaniach nie uczestniczyli ludzie ani ich materiały i dane. Żadne zwierzęta ani materiały pochodzenia zwierzęcego nie były wykorzystane w badaniach. Ze względu na wyłączne wykorzystanie ogólnodostępnych danych z Internetu opinia Komisji Bioetycznej nie była konieczna.

3.6 Wnioski

3.6.1. Popularniejszym określeniem jest „hidradenitis suppurativa" niż „acne inversa". Spośród dwóch określeń dla świądu, słowo „pruritus" jest powszechniej stosowane niż „itch" w najbardziej popularnych językach europejskich. Świerzbiączka jest najczęściej utożsamiana ze świerzbiączką guzkową, podczas gdy nowo zidentyfikowana choroba, świerzbiączka przewlekła pozostaje bardzo mało znana.

3.6.2. Ogólnodostępne artykuły online dotyczące AZS, HS, świądu i świerzbiączki są bardzo trudne do zrozumienia. Materiały opisujące chorobę skóry powodującą świąd jaką jest świerzbiączka, są trudniejsze do zrozumienia niż artykuły opisujące świąd sam w sobie. Artykuły używające określenia „itch" w opisie świądu są bardziej zrozumiałe niż te używające pojęcia „pruritus". Niedawno zdefiniowana dermatoza, świerzbiączka przewlekła jest opisywana w najmniej zrozumiały sposób. Najbardziej zrozumiała w opisie jest świerzbiączka guzkowa, która również jest najczęściej opisywanym typem świerzbiączki.

3.6.3 Artykuły napisane w języku angielskim, niderlandzkim i szwedzkim są najbardziej zrozumiałe dla czytelnika. Materiały w języku fińskim i węgierskim są najtrudniejsze do zrozumienia. Wpływ źródła artykułu na jego czytelność nie jest jednoznaczny.

3.6.4 Poziom czytelności artykułów dotyczących HS i AZS nie jest adekwatny dla dwóch z trzech potencjalnych europejskich pacjentów. Nienaukowe powszechnie dostępne materiały dotyczące świądu i świerzbiączki są zrozumiałe dla większości europejskiego społeczeństwa.

3.6.5 Najprawdopodobniej liczba potencjalnie dostępnych artykułów dotyczących chorób skóry nie jest skorelowana z ich czytelnością.

4. ARTYKUŁ PIERWSZY

Readability of Patient Electronic Materials for Atopic Dermatitis in 23 Languages: Analysis and Implications for Dermatologists

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ORIGINAL RESEARCH

Readability of Patient Electronic Materials for Atopic Dermatitis in 23 Languages: Analysis and Implications for Dermatologists

Tomasz Skrzypczak · Anna Skrzypczak · Jacek C. Szepietowski

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ABSTRACT

Introduction: Patients search on the Internet for information about various medical procedures and conditions. The main aim of this study was to evaluate the readability of online health information related to atopic dermatitis (AD). Online resources are becoming a standard in facilitating shared decision-making processes. With a pipeline of new therapeutic options like immunomodulators, understanding of the complexity of AD by the patients is crucial.

Methods: The term "atopic dermatitis" translated into 23 official European Union languages was searched using the Google search engine. The first 50 records in each language were evaluated for suitability. Included materials were barrier-free, focused on patient education, and were not categorized as advertisements. Article sources were classified into four categories: non-profit, online shops, pharmaceutical companies, and dermatology clinic. Readability was assessed with Lix score.

Results: A total of 615 articles in Swedish, Spanish, Slovenian, Slovak, Romanian, Portuguese, Polish, Lithuanian, Latvian, Irish, Italian, Hungarian, Greek, German, French, Finnish, Estonian, English, Dutch, Danish, Czech, Croatian, and Bulgarian were evaluated. The overall mean Lix score was 56 ± 8, which classified articles as very hard to comprehend. Significant differences in mean Lix scores were observed across all included languages (all $P < 0.001$). Articles released by non-profit organizations and pharmaceutical companies had the highest readability ($P < 0.001$). Low readability level was correlated with high article prevalence ($R^2 = 0.189$, $P = 0.031$).

Conclusions: Although there was an abundance of online articles related to AD, the readability of the available information was low. As online health information has become essential in making shared decisions between patients and physicians, an improvement in AD-related materials is needed.

Keywords: Atopic dermatitis; Internet content; Health information; Patient education

T. Skrzypczak
University Hospital in Wroclaw, Borowska 213, 50-556 Wroclaw, Poland
e-mail: t.skrzypczak.pl@gmail.com

A. Skrzypczak
Faculty of Dentistry, Wroclaw Medical University, Krakowska 26, 50-425 Wroclaw, Poland
e-mail: anusiaskrzypczak@gmail.com

J. C. Szepietowski (✉)
Chair of the Department of Dermatology, Venerology and Allergology, Wroclaw Medical University, Chalubinskiego 1, 50-368 Wroclaw, Poland
e-mail: jacek.szepietowski@umw.edu.pl

Key Summary Points

Why carry out this study?

Little was known about the readability of atopic dermatitis (AD) online health information.

The goal of the study was to examine the comprehensibility of AD-related materials across multiple languages and their origins.

What was learned from the study?

Although there was abundance of AD-related materials in 23 included languages, their readability was classified as very hard.

Articles offered by pharmaceutical companies and non-profit organizations were the most comprehensible.

Dermatologist should take action to ensure readable AD-related materials on the Internet.

INTRODUCTION

Atopic dermatitis (AD) is a common inflammatory pruritic skin disease with complex pathophysiology and clinical presentation [1–3]. AD causes dry skin, itchy rash, and has a great impact on quality of life (QoL) [3, 4]. Social and financial costs caused by AD lead to the largest global burden of disability related to skin diseases [3, 5]. Recent data suggest that the prevalence of AD is approximately 20% in children, and 7% in adults in the European Union (EU) [6].

There is no cure for AD, but it can be effectively controlled [2]. In recent years, a continuously expanding understanding of AD pathogenesis has led to rapidly evolving new therapeutic options [7]. Treatment costs are one of the most troubling burdens of AD [2]. In addition to prescribed medications, lifestyle modification is a pillar of AD therapy [8]. Patients are encouraged to purchase specific clothing, soaps, detergents, and emollients [8]. Financial costs and indirect expenses such as time spent on doctor's appointments emphasize the need for optimal AD management [2]. In the USA and Europe, treatment adherence was described as poor [9, 10]. It was found in the USA that only 32% of patients followed their topical treatment in AD [9]. In the UK nearly 50% of patients and caregivers could not correctly identify the potency of commonly prescribed topical corticosteroids [10]. In Australia, poor understanding of the disease, lack of knowledge, and the complexity of treatment regimens were identified as factors responsible for poor treatment outcomes [11]. Patient education was identified by worldwide recommendations to be crucial in improving treatment adherence and patients' QoL in AD [12, 13].

A recent study emphasized that English-speaking patients are utilizing the Internet to gain knowledge about their medical concerns and treatment options, underscored the accessibility, user-friendly interface, and low cost of online health information [14]. In the English-speaking world, the Internet is widely recognized as a trustworthy source of health information [14]. Individuals from these nations utilize online resources to enhance their own understanding and expand their expertise [14]. The desire for self-education through online materials was strong among Anglophone patients [15]. The most widely used web search engine, Google, allows patients to enter specific terms and receive a list of potential websites to address their inquiries [15]. Online information found in Google is a mix of articles dedicated to the public, journalists, health professionals, and patients [16]. Presented content is not regulated and significant quality variations were demonstrated on websites dedicated to various health conditions [17]. Health-related articles aimed at the public and patients may use complex medical terminology, resulting in an overestimation of readers' understanding and therefore potential confusion [16, 18]. "Readability" is a term used to describe the level of ease with which written material can be read. This factor is of great importance when evaluating the

comprehensibility of a patient-focused resource, as higher readability is typically linked to better understanding [16, 18]. It could not be excluded that low readability of online materials related to AD contributes to its poor management. Lack of understanding of the AD pathogenesis such as the itch–scratch cycle, skin conditioning methods, and proper treatment application could lead to poor patient adherence and management outcomes.

A few studies have assessed readability of patient electronic materials dedicated to skin diseases [1, 19, 20]. Only one study assessed patient electronic materials dedicated to AD [1]. It involved only 30 articles, and all were written in English [1], thus its results might not be reliable and generalizable to wider populations. No study was found that evaluated readability of patient electronic materials related to AD in multiple languages. No study has evaluated these materials' readability by its source. The main aim of this study was to evaluate readability of Google-searched materials related to AD written in European languages with a validated measure. The secondary aim was to compare readability of those materials by their source. Prevalence of those materials in the included languages was also investigated. Finally, correlation between article readability and prevalence was examined.

METHODS

The methodology utilized in this study closely resembled that of one of the author's other published work [18].

Search Method

Google Translate services were utilized to translate search term "atopic dermatitis" to official languages of the EU. Each term was queried in new session of Google search engine and a list of the search results was generated. Private mode of web browser was used and the same preferred country of Google Services as the language of the searched term was set up to ensure the reliability of the generated results list. For each language the first 50 search results obtained with the search term were collected because Internet users typically stop searching after the first 50 hits [18, 21]. Articles related to AD in both children and adults, free to the public, and focused on patient education were included. Results in languages other than the searched term as well as password and/or paywall protected content were excluded. Scientific articles, videos, personal blogs, online forums, and advertisements were also excluded. Websites that primarily advertised a particular drug, medical facility, or doctor and did not emphasize patient education were classified as advertisements [14, 18]. Articles released by regulatory bodies, dedicated to physicians or medical professionals, related to veterinary medicine or alternative medicine were omitted from the analysis. The EU has 24 official languages: Swedish, Spanish, Slovenian, Slovak, Romanian, Portuguese, Polish, Maltese, Lithuanian, Latvian, Italian, Irish, Hungarian, Greek, German, French, Finnish, Estonian, English, Dutch, Danish, Czech, Croatian, and Bulgarian [22]. Google Services did not support Maltese as a preferred search language [23] and was therefore not included in the analysis.

Source Classification

Non-profit

The patient electronic material source was non-profit if the article met the following criteria: (1) issued by a hospital, practice, or clinic whose statutory aim was not profit generation; (2) released by a non-profit organization that aimed to support people with AD, e.g., International Society of Atopic Dermatitis (ISAD), Association of People Affected by Atopic Dermatitis; (3) was posted on a website whose main purpose was not to encourage the reader to buy a certain drug, laboratory test, book a physician consultation, or purchase other appliances such as soaps, detergents, or emollients.

Online Shop

Although evaluated electronic material was not considered to be an advertisement, it was released by a website that offered online purchase of drugs (online pharmacies),

prescriptions, laboratory tests, physician consultations, etc.

Pharmaceutical Company
Evaluated material was not considered to be an advertisement, had purely educational nature but was released by a pharmaceutical company website (e.g., Sanofi). These articles included brand names, company names, or pop-up adverts, thus their for-profit nature was clear. If a website offered a purchase option, it was classified as an "online shop".

Dermatology Clinic
Included patient electronic material was posted by a group practice, individually practicing physician, hospital, or outpatient clinic. These did not promote a certain physician, clinic, or treatment option; however, their non-profit character could not be ensured. These web pages had a contact phone number, email, and address required to schedule a consultation or hospital admission. Similarly, if a website offered a purchase option (e.g., teleconsultation), it was classified as an "online shop".

Readability Assessment

The Lix formula, a proven measure of readability, was used to evaluate all included materials [24, 25]. In contrast to other metrics like the Gunning Fogg Index, Lix was demonstrated to be a trustworthy measure of readability in various languages (Swedish, Danish, English, French, German, Finnish, Italian, Spanish, Portuguese) [18, 24, 25]. It is considered by the scientific community to be a reliable readability measure for all European languages [18, 24, 25]. Not only is it easy to calculate and understand but it also overcomes challenges with syllabification, making it suitable for complex languages such as Chinese and Arabic [18, 24]. Evaluated text was copied into Microsoft Word and all extraneous text (e.g., affiliations, hyperlinks, figures, legends, disclaimers, adverts, author information, and copyright notices) was removed. The function "Save as Plain Text" was utilized. To check and correct spelling and grammar using Microsoft Word, the relevant language of the text was selected. Each article was saved as a separate file, and then text was copied to an online Lix calculator (https://haubergs.com/rix). The number of sentences, number of words, average number of words in a sentence, and Lix score were noted. To interpret the Lix score, the scale recommended by Anderson [25] was employed. Scores lower than 20 were labeled as very easy to understand, while those below 30 were categorized as easy, below 40 as a little hard, below 50 as hard, and below 60 as very hard to comprehend [25].

Statistical Analyses

Number of words, number of sentences, and mean Lix scores were compared across all analyzed languages with analysis of variance (ANOVA). Similarly, ANOVA was used to evaluate article parameters and their sources. Correlation between the mean Lix score of analyzed articles and the number of hits was examined with univariate linear regression analysis. Distribution of the data was evaluated with Shapiro–Wilk test. *P* value equal to or less than 0.05 was considered statistically significant. JASP version 0.17.1 (JASP Team, University of Amsterdam) was used to conduct analyses and Microsoft Word and Excel, version 16.59 (Redmont, USA) were used to aggregate the data.

Ethical Approval

This article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

RESULTS

Prevalence

Overall, 615 articles were included in the analysis. The most prevalent were articles in Italian (46 articles), Polish (38 articles), and Romanian (35 articles). Irish was the least popular language, with only one included material. The

Table 1 Number of hits and included articles per search term

Language	Search term	Total # of hits	Included articles *n* (%)
Bulgarian	атопичен дерматит	217,000	24 (48)
Croatian	atopijski dermatitis	1,190,000	21 (42)
Czech	atopická dermatitida	123,000	22 (44)
Danish	Atopisk dermatitis	480,000	15 (30)
Dutch	atopische dermatitis	439,000	21 (42)
English	atopic dermatitis	147,000,000	30 (60)
Estonian	atoopiline dermatiit	114,000	21 (42)
Finnish	atooppinen ihottuma	125,000	25 (50)
French	la dermatite atopique	918,000	29 (58)
German	atopische Dermatitis	433,000	26 (52)
Greek	ατοπική δερματίτιδα	507,000	33 (66)
Hungarian	atópiás dermatitisz	71,100	29 (58)
Irish	dheirmitíteas atópacha	218	1 (2)
Italian	dermatite atopica	4,520,000	46 (92)
Latvian	atopiskais dermatīts	N/A	22 (44)
Lithuanian	atopinis dermatitas	131,000	33 (66)
Polish	atopowe zapalenie skóry	5,890,000	38 (76)
Portuguese	dermatite atópica	2,760,000	26 (52)
Romanian	dermatita atopica	N/A	35 (70)
Slovak	atopická dermatitída	68,900	25 (50)
Slovenian	atopijski dermatitis	1,270,000	33 (66)
Spanish	dermatitis atópica	6,490,000	33 (66)
Swedish	atopisk dermatit	86,000	27 (54)

number, N/A not available. Percentage values were calculated out of 50 articles included in the search results list

numbers of hits were the highest for English (147,000,000), Spanish (6,490,000), and Polish (5,890,000). Irish had the lowest number of hits (218). Searched queries, number of search hits, and number of included websites for each language are presented in Table 1.

Readability Assessment

The articles examined had an overall mean of 56 ± 8 for Lix score, 1152 ± 834 for word count, 74 ± 60 for sentence count, and 16 ± 4 for average words per sentence. Statistical significance was found in all differences between languages ($P < 0.001$ for all). Table 2 provides the exact values for all included languages.

Table 2 Readability of atopic dermatitis related articles in EU languages

Language	Lix score	# Sentences	# Words	# Words/sentence
Bulgarian	56 ± 6	50 ± 43	831 ± 685	17 ± 3
Croatian	57 ± 6	92 ± 96	1445 ± 1488	16 ± 2
Czech	55 ± 6	69 ± 47	979 ± 686	15 ± 4
Danish	49 ± 8	69 ± 29	1214 ± 829	17 ± 5
Dutch	47 ± 5	97 ± 75	1383 ± 982	14 ± 2
English	42 ± 6	96 ± 63	1448 ± 991	16 ± 4
Estonian	63 ± 5	53 ± 30	677 ± 368	13 ± 3
Finnish	68 ± 6	75 ± 46	847 ± 544	12 ± 2
French	56 ± 5	66 ± 43	1182 ± 723	19 ± 3
German	54 ± 5	142 ± 155	1791 ± 1512	13 ± 2
Greek	57 ± 6	50 ± 38	943 ± 656	20 ± 5
Hungarian	65 ± 5	60 ± 39	814 ± 505	14 ± 3
Irish	54 ± N/A	19 ± N/A	425 ± N/A	22 ± N/A
Italian	60 ± 6	60 ± 39	1194 ± 756	21 ± 4
Latvian	62 ± 5	68 ± 36	1006 ± 494	15 ± 3
Lithuanian	64 ± 7	55 ± 31	708 ± 348	14 ± 4
Polish	61 ± 4	93 ± 71	1368 ± 901	15 ± 2
Portuguese	53 ± 3	71 ± 46	1324 ± 902	19 ± 3
Romanian	61 ± 7	61 ± 27	1212 ± 529	21 ± 5
Slovak	58 ± 5	100 ± 44	1485 ± 793	15 ± 3
Slovenian	54 ± 5	77 ± 44	1151 ± 586	15 ± 2
Spanish	50 ± 5	80 ± 51	1382 ± 926	18 ± 3
Swedish	47 ± 7	58 ± 39	888 ± 503	16 ± 4

Data are presented as mean ± standard deviation. # number, N/A not available. Only 1 article in Irish was included in the analysis, thus standard deviation calculation was irrelevant. Differences between Lix score, number of sentences, words, and words/sentence were statistically significant. All $P < 0.001$

English (42 ± 6), Dutch (47 ± 5), and Swedish (47 ± 7) were the languages that yielded the most readable articles. Articles in Finnish (68 ± 6), Hungarian (65 ± 5), and Lithuanian (64 ± 7) were the most challenging to understand. None of the articles in the included languages had a Lix score lower than 30 or 40; thus, they were not considered easy or a little hard to understand [18, 25, 26]. Articles in English, Dutch, Swedish and Danish were classified as hard to comprehend [18, 25, 26]. Articles in remaining languages were classified as very hard to comprehend. Figure 1 illustrates the mean Lix values.

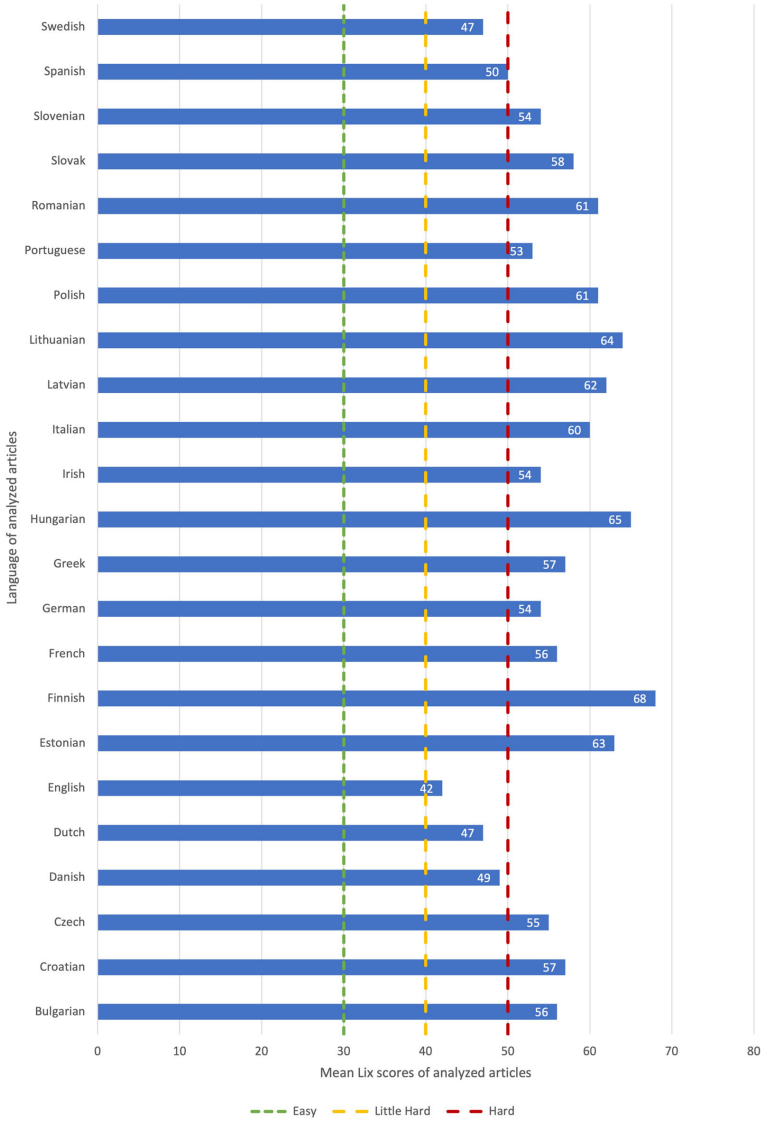

Fig. 1 Readability of atopic dermatitis-related online patient electronic materials in European languages. Mean Lix score was rounded to the nearest integer. Text is classified as easy to comprehend if Lix < 30, as a little hard if Lix < 40, as hard if Lix < 50

Articles in German (142 ± 155), Slovak (100 ± 44), and Dutch (97 ± 75) had the highest average number of sentencesArticles in Bulgarian (50 ± 43), Greek (50 ± 38), and Estonian (53 ± 30) had the lowest average number of sentences. Articles in German (1791 ± 1512), Slovak (1485 ± 793), and English (1448 ± 991) had the highest average number of words per article. The opposite was revealed for articles in Estonian (678 ± 368), Lithuanian (708 ± 348), and Hungarian (814 ± 505). Articles with the highest words/sentence ratios were in Italian (21 ± 4), Romanian (21 ± 5), and Greek (20 ± 5). The opposite was revealed for articles in Finnish (12 ± 2), Estonian (13 ± 3), and German (13 ± 2).

Readability and Article Source

The highest numbers of words per article were observed for non-profit sources (1276 ± 992). Articles issued by pharmaceutical companies had the lowest number of words per article (735 ± 486). The difference between number of words per article and its source was statistically significant ($P = 0.023$). Differences between number of sentences and average number of words in a sentence per article were not statistically significant ($P = 0.101$ and $P = 0.490$, respectively). Mean values are presented in Table 3.

Articles issued by pharmaceutical companies (56 ± 8) and non-profit organizations (56 ± 9) had the highest readability. The lowest readability was revealed for articles released by source classified as dermatology clinic (59 ± 8) and online shop (58 ± 7). Articles in all sources had average Lix score > 50 and were classified as very hard to comprehend. The differences were statistically significant ($P < 0.001$). Mean Lix values by source class are presented in Fig. 2.

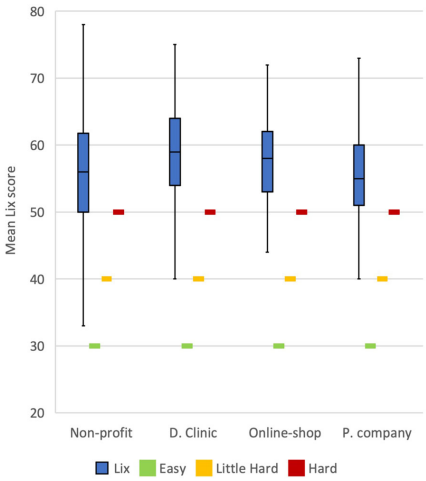

Fig. 2 Mean Lix values of analyzed articles by source. D = dermatology, P = pharmaceutical; text is classified as easy to comprehend if Lix < 30, as a little hard if Lix < 40, as hard if Lix < 50. $P < 0.001$

Table 3 Readability of atopic dermatitis related articles

Source	Lix score	# Sentences	# Words	# Words/sentence
Non-profit	56 ± 9	81 ± 76	1276 ± 992	17 ± 4
D. clinic	59 ± 8	68 ± 61	1043 ± 849	17 ± 4
Online shop	58 ± 7	65 ± 30	1009 ± 1160	16 ± 4
P. company	56 ± 8	75 ± 47	735 ± 486	16 ± 4
P value	< 0.001	0.101*	0.023	0.490*

P. pharmaceutical, D. dermatology, # number of. All values are presented as mean ± standard deviation. *P* was calculated with analysis of variance (ANOVA)
*These results were not statistically significant

Prevalence and Readability

Univariate linear regression was performed to examine correlation between readability of AD-related online materials and number of Google search hits. There was a weak positive correlation between mean Lix scores and number of hits ($R^2 = 0.189$, $P = 0.031$). The rise in prevalence of AD-related materials is associated with a decrease in their comprehensibility.

DISCUSSION

Although the Internet provides a great number of materials about AD, the comprehensibility of those information was revealed to be not optimal; no materials in any included languages were categorized as easy to comprehend, which highlighted this fact. Articles in 4 out of 23 included languages (English, Dutch, Swedish, and Danish) were classified as hard to comprehend. Articles in the majority of included languages (19 out of 23) were categorized as very hard. The presented results demonstrated also that articles released by non-profit organizations and pharmaceutical companies had the highest comprehensibility. The commercial background of AD-related materials was related to their lower readability. Articles issued by online shops and dermatology clinics had substantially lower comprehensibility levels. Quantity did not equate to readability in the context of online AD materials. The mean Lix scores did not correlate with number of hits.

Overall mean Lix score was 56 ± 8, which corresponds to college-grade level [27]. In the EU, only 32% of the population had completed tertiary education [28]. These facts mean that only one out of three potential patients can understand AD-related information found on the Internet. It was demonstrated that reliable patient self-education improves AD therapy outcomes both in paper-based and online form [29, 30]. Booklets that contained information on important everyday patient-oriented aspects of AD significantly improved the emotional status of patients with AD [2, 29]. Similarly, online educational materials proved to be helpful in the management of patients with AD [2, 30]. Self-education with reliable online electronic materials led to significant improvement in AD symptoms and QoL [30]. Online materials demonstrated greater effectiveness of education in patients with AD [31].

In all included languages, low comprehensibility of online AD-related materials was revealed. Without sufficient understanding of the disease, its complexity, and treatment options, it is difficult for patients to maintain sufficient compliance. It seems reasonable to assume that introduction of comprehensible AD-related online educational materials would potentially improve AD treatment outcomes and reduce social and economic global burden of the disease. Although articles released by non-profit organizations and pharmaceutical companies were found to have the greatest readability, both had readability level classified as very hard. Similar results were revealed in other medical specialties such as gynecology and ophthalmology [32–34]. These facts have implications, which are discussed below.

First, non-profit organizations and clinics, such as major associations focused on AD or academic hospitals, should improve comprehensibility of distributed information. Although associations often aim to educate health professionals, they could focus more on reliable patient education. Tertiary hospitals that teach students and medical professionals could also spread their expertise to the public in the form that layman can understand. In the age of disinformation, trusted sources should offer materials that meet the needs of the average Internet user.

Although articles released by pharmaceutical companies had higher levels of comprehensibility, there is scope for further improvement. Comprehensible online educational materials associated with certain manufacturers would benefit both company and patients. Patients with a good understanding of their therapy would have a better treatment adherence. It seems reasonable that with good compliance, satisfactory treatment outcomes could be associated with the company that released a certain article.

Secondly, reliable materials must be chosen by patients to fulfil their functions. Web

promotion is possible through Google's search engine [18, 35]. Internet users were more likely to visit websites that were promoted and were positioned at the top of search results [18, 35]. Encouraging the circulation of reliable and engaging online content could prove beneficial for the average Internet user. Top-searched materials written in European languages potentially would improve AD treatment outcomes. The economic and social burden of AD could be not only reduced in European countries but also in countries whose official languages are the same as in the EU (e.g., Portuguese in Brazil).

The present investigation revealed a correlation between readability and material abundance: greater prevalence of materials was associated with lower comprehensibility. This correlation was very weak ($R^2 = 0.189$). Although it is contrary to results within other specialties [14, 18], it can reasonably be assumed that greater quantity is related to worse readability.

Articles in Italian, Polish, and Romanian were the most prevalent. Irish was the least popular language with only one included article. These observations could be explained by the following facts. Irish is a decaying language with only a few people speaking Irish [36]. It seems reasonable that there was little or no interest in creating materials that were dedicated to a very limited group of patients. In Italy, Poland, and Romania, the public sector is limited and an ambulatory practice such as dermatology is run on a private ownership basis [37–39]. Consequently, private practices could release more online materials, to grab the attention of potential patients and ensure an adequate volume of visits.

Several other readability investigations dedicated to other dermatoses demonstrated similar deficits and highlighted the need for the improvement of online health materials [20, 40]. With the emerging pipeline of immunomodulators in AD treatment, it is increasingly important for online health information to reflect new therapeutic options [40]. Online resources are becoming a standard in patient care and facilitate successful shared decision-making processes between physicians and patients [41]. All of these suggest an overwhelming need for improved readability of online materials related to AD.

Although the present study evaluated the readability of online educational materials related to AD, the quality of the presented information remained unknown. DISCERN and JAMA instruments were designed to assess the quality of the data found on the Internet [42, 43]. As a result of the number of languages evaluated, the authors focused only on readability. These instruments require fluency in the language of the assessed article, something that the authors could not ensure for all included languages. Low readability and quality of online materials have been the subject of debate since the Internet became popular. It was always difficult to encourage enhancement of the materials presented on the Internet. One initiative was Health On the Net (HON) certification [44, 45]. Website administrators applied to the HON organization and sent source code of the website [45]. When the certification was granted, the webpage could display the HON logo [45]. If presented information did not adhere to the HON policy, the organization asked administrator to amend presented data [45]. Patients could identify trustworthy website by the HON logo, which facilitated reliable information finding on the Internet [45]. Unfortunately, this initiative was almost unknown and was permanently discontinued in December 2022 [46]. Now, the problem of reliability of the online information is even more critical than at the beginning of the Internet era. With the introduction of artificial intelligence models such as ChatGPT, the Internet is being flooded with unreliable materials [47]. These are often undistinguishable from human-written materials and often lead to patient disinformation [47].

All included materials were evaluated with Lix score. Lix was originally designed to evaluate readability of newspapers articles written in Swedish [25]. The accuracy of this readability measure was tested and approved in a variety of languages (Danish, English, Finnish, French, German, Italian, Portuguese, Swedish, Spanish) [24–26, 48]. There were no studies that evaluated Lix for other included languages. This

could potentially limit the presented investigation. However, Lix is considered by the scientific community as a reliable readability measure for all European languages [24, 25]. Although levels of comprehensibility applied in this study were designed for Danish, Swedish, Norwegian, and Dutch [24–26, 48], it could not be excluded that different cutoffs would be more suitable for other included languages. The Google search results are dynamic and could vary according to the geographic location of the search time and date. This study was conducted in Poland. Google search results were generated and evaluated between 26 December 2023 and 11 January 2024. It could not be excluded that data collection conducted in another country would bring different results. Similarly, the selection of Google as the search engine could bias the results. Quality evaluation of the analyzed articles with validated instruments was not performed, which is also important in the context of online health information. Nevertheless, this was beyond the designated scope of the study and may warrant further investigation in the future.

CONCLUSION

Although the Internet provides plenty of easily accessible materials related to AD, the readability of the presented information is low. Only one out of three patients could understand AD-related online health information. Non-profit organizations and pharmaceutical companies released online materials with the lowest Lix scores; however, the comprehensibility of their materials was classified as very hard. Online materials are becoming a standard in patient care and essential in making shared decisions between patients and physicians. An improvement in online AD-related online materials is needed.

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Data Availability. The datasets generated and analyzed during the current study are available in the Google Drive repository, https://drive.google.com/drive/folders/1MbnFeDq6f8M8Xy1Y9iBvZCNZ-dk9HpIG?usp=share_link.

Declarations

Conflict of Interest. Jacek C. Szepietowski has served as an advisor for AbbVie, LEO Pharma, Menlo Therapeutics, Novartis, Pierre Fabre, Sienna Biopharmaceuticals, and Trevi; has received speaker honoraria from AbbVie, Eli Lilly, Janssen, LEO Pharma, Novartis, Sanofi-Genzyme, Sun Pharma, and Berlin-Chemie Men-narini; has served as an investigator; and has received funding from AbbVie, Amgen, Galapagos, Holm, Incyte Corporation, InflaRX, Janssen, Menlo Therapeutics, Merck, Boehringer Ingelheim, Novartis, Pfizer, Regeneron, Trevi, and UCB. Tomasz & Anna Skrzypczak report no conflict of interest.

Ethical Approval. This article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

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5. ARTYKUŁ DRUGI

Hidradenitis Suppurativa Online Documents Readability: An Analysis Including 23 European Languages

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ORIGINAL RESEARCH

Hidradenitis Suppurativa Online Documents Readability: An Analysis Including 23 European Languages

Tomasz Skrzypczak[1], Anna Skrzypczak[2], Jacek C Szepietowski[1]

[1]Department of Dermatology, Venereology and Allergology, Wroclaw Medical University, Wroclaw, Poland; [2]Department of Periodontology, Wroclaw Medical University, Wroclaw, Poland

Correspondence: Jacek C Szepietowski, Chair of the Department of Dermatology, Venereology and Allergology, Wroclaw Medical University, Chalubinskiego, Wroclaw, 1 50-368, Poland, Email jacek.szepietowski@umw.edu.pl

Purpose: Hidradenitis suppurativa (HS) is a complex disease with the vast burden to patients. The aim of the study was to evaluate readability of online electronic materials dedicated to HS.

Patients and Methods: The terms "hidradenitis suppurativa" and "acne inversa" translated into 23 official European Union languages were searched with Google. For each language, first 50 results were assessed for suitability. Included materials were focused on patient's education, had no barriers and were not advertisements. If both terms generated the same results, duplicated materials were excluded from the analysis. Origin of the article was categorized into non-profit, online-shop, dermatology clinic or pharmaceutical company class. Readability was evaluated with Lix score.

Results: A total of 458 articles in 22 languages were evaluated. The overall mean Lix score was 57 ± 9. This classified included articles as very hard to comprehend. Across all included languages significant differences in Lix score were revealed ($P < 0.001$). No significant differences across all origin categories and Lix scores were observed (all $P > 0.05$).

Conclusion: Despite the coverage of HS on the Internet, its complexity made it hard to comprehend. Dermatologist should ensure readable, barrier-free online educational materials. With adequate Google promotion, these would be beneficial for both physicians and patients.

Keywords: hidradenitis suppurativa, online education, acne inversa, readability

Introduction

Hidradenitis Suppurativa (HS) is a chronic, inflammatory skin condition that typically occurs after puberty and is characterized by recurring painful nodules, abscesses, sinus tracts, and scarring.[1] It is the most prevalent in the inverse areas of the skin.[1]

The estimated prevalence of HS is about 1%, but unfortunately, there is a significant delay of nearly 9 years in the diagnosis and initiation of suitable treatment.[2–5] Limited understanding of the disease often leads to misdiagnosis of HS by both healthcare professionals and patients.[1] In addition, the affected localized regions (mainly in the intimate area), the clinical presentation, and the long-term nature of the symptoms all serve as major challenges for patients in discussing their disease and seeking medical advice.[6] While mild HS is typically manageable, traditional methods may not be successful in treating more severe cases of the disease.[7,8] Biologic treatment has emerged as a promising new therapeutic option in recent research.[7,8] Although these new medications show great potential, their high cost and limited availability make them uncommon in everyday clinical practice.[7,8] As a result, HS patients are highly motivated to seek out information on their clinical symptoms, condition and available treatment through online resources, granting them the ability to acquire disease-specific information rapidly and privately.[5]

The increasing trend of using the Internet to make personal health decisions is widely recognized. According to survey results, 70% of American adults who use the Internet selected it as their primary diagnostic resource, making it

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the third most favored online activity for personal health purposes.[8–11] A notable 67% of Internet users consider online health information to be a key factor in their decision-making, emphasizing the importance of reliable sources.[12] It seems reasonable to assume that readability of information found on the Internet is crucial in shared decision-making process between patients and physicians.

There was limited information on the readability of patient electronic materials dedicated to HS. Only readability of HS materials written in English was assessed in previous investigations.[13–15] These studies classified the examined articles as from dermatologists, non-dermatologists, and non-physicians, potentially limiting the generalizability of their findings.[13–15] No study examined the correlation between articles abundance and their readability. Finally, previous studies were constrained by the amount of data analyzed. They focused solely on the top 50 results from one Google search in one language, potentially limiting the evidence presented.[13–15]

The main aim of this study was to conduct multilingual readability analysis of HS-related online materials. Also, prevalence of those materials in included languages was evaluated. The secondary aim was to compare readability of those materials by their source. Finally, correlation between articles abundance and their comprehensibility was examined.

Materials and Methods

The methodology utilized in this study closely resembled that of others author's published works.[16,17]

Search Method

In this study terms "hidradenitis suppurativa" and "acne inversa" were utilized. Each of them was translated into 23 official European Union (EU) languages. A list of search results was then generated by querying each term in a new session of the Google search engine. Combined search terms such as "hidradenitis suppurativa treatment", "acne inversa symptoms" and other possible combinations with related words led to similar results lists. They consisted mainly of records that duplicated these obtained with "hidradenitis suppurativa" and "acne inversa". As a result, combined search terms were not included in the study. Throughout the years, Google remained the most popular internet search engine with over 90% of market share across all devices.[18] Although some patients would prefer using other search engines, their market share was drastically lower, with approximately 3% for Bing, 1% for Yahoo and less than 1% for DuckDuckGo.[18] As a result, these search engines were not included in the analysis. Google often displays articles labeled as "Sponsored" at the top of the search list. These articles were excluded from the analysis. To maintain the credibility of the results, the web browser's private mode was employed and the language for Google Services was set to the language of the searched term.[19] For each session, "Results Language Filter" was encompassed, to ensure that presented results were only in the desired language.[19] This methodology was in accordance with Google's guidelines for searching materials in different languages.[19] Duplicated results were excluded from the analysis if the search results were identical for both terms. The first 50 search results for one term in each language were collected and examined. It was established through previous research that most internet users do not read past the initial 50 hits.[20–23] Articles related to HS, free to public and focused on patient education were included. Results that were not in the searched term's language, as well as those that required a password or were behind a paywall, were not included in the analysis. Furthermore, scientific articles, videos, personal blogs, online forums, and advertisements were excluded. A website was classified as an advertisement if primarily contained promotional material for a specific drug, medical center, physician and/or did not have focus on patient education.[17,23] Articles dedicated to medical professionals, physicians, released by regulatory bodies or related to veterinary medicine were ruled out from the analysis. The EU has 24 official languages: Bulgarian, Croatian, Czech, Danish, Dutch, English, Estonian, Finnish, French, German, Greek, Hungarian, Irish, Italian, Latvian, Lithuanian, Maltese, Polish, Portuguese, Romanian, Slovak, Slovenian, Spanish and Swedish.[24] Google Services did not support Maltese as preferred language of search.[25] This language was not included in the analysis.

Readability Assessment

A validated readability measure, Lix was utilized to assess all included materials.[26,27] Unlike other measures (eg, the Gunning Fogg Index), Lix was proved to be reliable readability measure across several languages (Swedish, Danish, English,

French, German, Finnish, Italian, Spanish, Portuguese).[17,23,26,27] It is considered by scientific community to be a reliable readability measure for all European languages.[17,23,26,27] Apart from being easy to calculate and interpret, it bypasses issues with syllabification, which makes it suitable for even such complex languages such as Chinese and Arabic.[17,23,26,27] The text was transferred to Microsoft Word and then examined, with any unnecessary elements such as affiliations, hyperlinks, figures, legends, disclaimers, adverts, authors information, and copyright notices eliminated. The function "Save as Plain Text" was employed. Microsoft Word was used to proofread and amend any spelling and grammar issues by selecting the appropriate language for the text. Each article was stored as its own file, and the text was subsequently pasted into the Lix calculator on https://haubergs.com/rix. The total amount of sentences, words, and average words per sentence, along with the Lix score, were recorded. To interpret Lix score, scale proposed by *Anderson* was utilized.[27] Text with score <20 was classified as very easy to comprehend, <30 easy, <40 little hard, <50 hard, and <60 very hard to comprehend.[27]

Source Classification

Online Shop

Even though the website allowed for online purchases of drugs, prescriptions, laboratory tests, or physician consultations, the released electronic material was not classified as advertisement during the evaluation.

Pharmaceutical Company

The assessed material was not classified as advertisement, it was solely intended for educational purposes and was distributed through the website of a pharmaceutical company (eg, Novartis). The clear presence of brand names, company names, and pop-up adverts in these articles indicated that they were created with a for-profit motive. If there was an option to make purchases on the website, it fell under the category of an "online shop."

Dermatologic Clinic

Patient electronic material was distributed by the group practice, individual physicians, hospitals, or outpatient clinics. Despite not endorsing any doctor, clinic, or treatment, their non-profit nature was not guaranteed. These web pages contained the necessary contact information, including a phone number, email, and address, for scheduling a consultation or hospital admission. Correspondingly, a website that presented a buying option (such as teleconsultations) was classified as an "online shop."

Non – Profit

If the article met the following guidelines, the source of the patient electronic material was deemed non-profit: 1) Released by a hospital, practice, or clinic with the primary objective of not generating profit; 2) Published by a non-profit organization committed to aiding those with HS, such as "HS Foundation"; 3) was posted on the website, that its main purpose was not to encourage reader to buy certain drug, laboratory test, book physician consultation or other appliances.

Statistical Analyses

Distribution of the data was evaluated with Shapiro–Wilk test. Across all analyzed languages and origins number of words, sentences, words in one sentence and Lix scores were compared with analysis of variance (ANOVA) or Kruskal–Wallis's test. Univariate linear regression analysis was utilized to examine correlation between mean Lix score of analyzed articles and number of hits. P value equal or less than 0.05 was statistically significant. Microsoft Word and Excel, version 16.59 (Redmond, USA) was used to aggregate the data. JASP version 16.59 (JASP Team, University of Amsterdam) was utilized to conduct statistical analyses.

Ethical Approval

The study did not involve any animals or animal-based materials. Human participants and their materials and data were also not involved in this study. The utilization of Internet data alone made ethical approval unnecessary.

Results

Prevalence

In general, 458 articles were included in the analysis. A total of 306 articles were received with search term "hidradenitis suppurativa" and 152 with "acne inversa". There were no statistically significant differences in Lix score; number of words, sentences, and words per sentence between articles obtained with translations of "hidradenitis suppurativa" and "acne inversa" (P = 0.202; 0.884; 0.567; 0.089, respectively). The most prevalent were articles in Polish (40 articles, 9%), Spanish (39 articles, 9%) and English (38 articles, 8%). Languages with the lowest number of articles were Croatian (1 article, 0%), Czech (3 articles 1%) and Slovak (4 articles, 1%). No Irish articles met the inclusion criteria and was included in the analysis. The highest cumulative number of hits was revealed for German (6.8 million), English (6.5 million) and Czech (6.3 million). The lowest number of total hits was observed for Croatia (6.5 thousand), Bulgaria (8.7 thousand) and Latvia (18.9 thousand). Numbers of hits were not available for Hungarian, Irish, Portuguese, Slovenian and for "acne inversa" in Swedish. Number of included websites, searched queries, and hits was presented in Table 1.

Table 1 Number of Included Online Materials and Hits per Language and Search Term

Language	Search term For HS and AI	Total # hits	Included Websites n (%)
Bulgarian	гноен хидраденит	7340	15(30)
	акне инверса	1320	10(20)
Croatian	Višestruki aksilarni apscesi	3960	0(0)
	Invertirane akne	2590	1(2)
Czech	Hidradenitis suppurativa	5,560,000	3(6)
	Reverzní akné	731,000	0(0)
Danish	Hidradenitis suppurativa	38,600	10(20)
	Akne inversa	37,300	3(6)
Dutch	Hidradenitis suppurativa	5,370,000	24(48)
	Acne ectopica	29,600	8(16)
English	Hidradenitis suppurativa	5,580,000	29(58)
	Acne inversa	953,000	9(18)
Estonian	Suppurativa hidradeniit	484	6(12)
	Akne inversa	186,000	0(0)
Finnish	Hidradenitis suppurativa	4,010,000	6(12)
	Taiveakne	5700	8(16)
French	Hidradénite suppurée	16,100	25(50)
	Acné inversée	89,300	11(22)
German	Hidradenitis suppurativa	5,980,000	10(20)
	Acne inversa	787,000	23(46)
Greek	Υδραδενίτιδα πυώδης	134	15(30)
	αντιστροφη ακμη	94,900	9(18)
Hungarian	Hidradenitis suppurativa	N/A	6(12)
	Acne inversa	N/A	3(6)
Irish	Hidradenitis suppurativa	N/A	N/A
	Acne inversa	N/A	N/A
Italian	Idrosadenite suppurativa	28,600	31(62)
	Acne inversa	873,000	6(12)
Latvian	Suppurativa hidradenīts	222	9(18)
	Pinnes otrādi	18,700	0(0)
Lithuanian	Hidradenitas Pūlingas	1500	7(14)
	Acne inversa	987,000	0(0)
Polish	Ropnie mnogie pach	2460	13(26)
	Trądzik odwrócony	45,200	27(54)

(*Continued*)

Table 1 (Continued).

Language	Search term For HS and AI	Total # hits	Included Websites n (%)
Portuguese	Hidrosadenite	N/A	22(44)
	Acne inversa	N/A	7(14)
Romanian	Hidradenita supurativă	5890	17(34)
	Acnee inversa	14,600	10(20)
Slovak	Hidradenitis suppurativa	5,030,000	2(4)
	Acne inversa	912,000	2(4)
Slovenian	Supurativni hidradenitis	N/A	11(22)
	Acne inversa	N/A	N/A
Spanish	Hidrosadenitis supurativa	28,100	30(60)
	Acné inverso	153,000	9(18)
Swedish	Hidradenitis suppurativa	5,400,000	15(30)
	Acne inversa	N/A	6(12)

Abbreviations: HS, Hidradenitis Suppurativa; AI, Acne Inversa; #, number of; N/A, not available.

Readability Evaluation

In general, mean values for analyzed articles were 57 ± 9 for Lix score, 56 ± 53 for number of sentences, 860 ± 732 for number of words and 17 ± 5 for average words in sentence. All differences were statistically significant (all $P < 0.001$) and are presented in Table 2.

Table 2 Readability of Hidradenitis Suppurativa Related Articles in European Languages

Language	Lix Score	#Sentences	#Words	#Words/Sentence
Bulgarian	56±6	55±35	868±618	16±4
Croatian	53±N/A	40±N/A	518±N/A	13±N/A
Czech	60±6	37±36	662±690	17±3
Danish	53±15	38±18	676±345	18±9
Dutch	48±5	67±54	912±731	14±2
English	48±10	93±59	1401±819	16±6
Estonian	64±11	59±47	764±564	15±4
Finnish	68±9	82±72	929±837	11±1
French	56±5	54±49	948±810	19±4
German	56±5	63±38	848±450	14±2
Greek	60±5	42±34	817±605	20±4
Hungarian	64±12	31±14	409±194	14±5
Irish	N/A±N/A	N/A±N/A	N/A±N/A	N/A±N/A
Italian	63±7	53±109	925±1416	21±6
Latvian	58±6	68±81	801±851	13±3
Lithuanian	63±4	37±19	478±268	13±3
Polish	66±6	41±22	581±303	15±3
Portuguese	54±6	33±21	615±384	19±3
Romanian	58±5	64±36	1019±623	17±4
Slovak	60±8	82±107	1210±1541	16±2
Slovenian	55±10	57±44	882±602	16±3
Spanish	54±8	51±40	836±562	19±6
Swedish	49±5	49±28	697±346	15±3

Notes: Data were presented as mean only 1 article in Croatian was included in the analysis, thus standard deviation calculation was irrelevant. No articles in Irish were included. Differences between lix score, number of sentences, words and words/sentence were statistically significant. All $P<0.001$. Lix was normally distributed, and P was calculated with ANOVA test. Number of sentences, words and average words in sentence were not normally distributed and respective P were calculated with Kruskal–Wallis's test.

Abbreviations: ±, standard deviation; #, Stands for number; N/A, not available.

Articles in English (48 ± 10), Dutch (49 ± 5) and Swedish (49 ± 5) had the lowest mean Lix scores and were the most comprehensible. The highest mean Lix scores were revealed for articles in Finnish (68 ± 9), Polish (66 ± 6) and Hungarian (64 ± 12). Articles in these languages were the most difficult to comprehend. The mean Lix values are presented in Figure 1.

No articles in included languages had mean Lix score <30 or <40 and were classified as easy or little hard to comprehend. Articles in Dutch, English and Swedish were classified as hard to comprehend. Articles in remaining languages were classified as very hard to comprehend. The highest average number of sentences per article were found for English (93 ± 59), Slovak (82 ± 107) and Finnish (82 ± 72). The lowest average number of sentences were found for Hungarian (31 ± 14), Portuguese (33 ± 21) and Czech (37 ± 35). Articles in English (1401 ± 819), Slovak (1210 ± 1541) and Romanian (1018 ± 623) had the highest mean number of words. The opposite was observed for articles in Hungarian (409 ± 194), Lithuanian (478 ± 268) and Polish (581 ± 303). The highest mean number of words per sentence was observed for Italian (21 ± 6), Greek (20 ± 4) and Portuguese (19 ± 3). The opposite was revealed for articles in Finnish (11 ± 1), Latvian (13 ± 3) and Lithuanian (13 ± 2).

Readability and Origin

There was no statistically significant difference between Lix score and origin of the articles (P = 0.670). Differences between origin of the article and words/sentence ratio per article were also not statistically significant

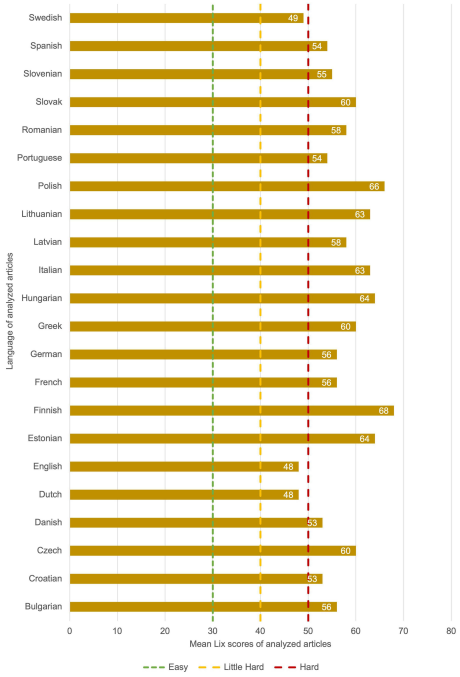

Figure 1 Title: Mean Lix scores of articles in the included languages.
Notes: Readability of hidradenitis suppurativa online articles in European languages. No articles in Irish met inclusion criteria. Maltese language was excluded. Google engine did not support this language. Easy refers to Lix score <30 and classifies text as easy to comprehend. Little hard refers to Lix score <40 and classifies text as little hard to comprehend. Hard refers to Lix score <50 and classifies text as hard to comprehend.

Table 3 Readability of Hidradenitis Suppurativa Related Articles by Their Origin

Source	Lix score	# Sentences	# Words	# Words/Sentence
Non-profit	56 ± 9	57 ± 60	878 ± 821	17 ± 5
D. Clinic	56 ±9	49 ± 38	749 ± 504	17 ± 4
Online-Shop	58 ± 9	75 ± 51	1148 ± 720	16 ± 5
P. Company	58 ± 11	46 ± 39	713 ± 573	16 ± 5
P value	0.670*	0.015	<0.001	0.679*

Notes: All values were presented as mean Lix was normally distributed, and *P* was calculated with ANOVA test. Number of sentences, words, and average words in sentence in article were not normally distributed and respective *P* were calculated with Kruskal–Wallis's test. *These results were not statistically significant.
Abbreviations: P, pharmaceutical; D, dermatology, #, number of; ±, standard deviation.

(P = 0.679). The lowest mean number of words was observed for articles released by pharmaceutical companies (713 ± 573) and dermatology clinic (749 ± 504). The opposite was observed for online shops (1148 ± 720) and non-profit organizations (878 ± 821). Articles released by online shops (75 ± 51) and non-profit organizations (57 ± 60) had the highest number of sentences per article. Dermatologic clinics (49 ± 38) and pharmaceutical companies (46 ± 39) released articles with the lowest number of sentences per article. Detailed data was presented in Table 3.

Prevalence and Readability

Univariate linear regression analysis was calculated to examine correlation between number of Google search hits and readability of included articles. No significant correlation was revealed (R^2 = 0.086, P = 0.224).

Discussion

Presented results suggests that while the internet offers a wealth of knowledge about HS, the comprehensiveness of the available materials is not optimal. This fact is underscored by the classification of materials in any included languages as easy to comprehend. The materials in Dutch, English, and Swedish were the only ones out of 23 languages that were classified as little hard to comprehend. The readability level of materials in other languages was classified as very hard. The results indicated that the origin of online materials had no effect on this difficulty. The included materials across all source classes showed no statistically significant differences in readability levels. The data presented that the volume of information did not translate to clarity when it comes to online HS-related content. There was no correlation between the number of hits and the mean Lix scores. These facts bring following implications.

HS is a complex disease that poses difficulties in diagnosis. It was demonstrated that the identification of HS following the primary manifestation of symptoms varied between 3 and 10 years, while most of the research found a delay of 6 to 10 years.[28] It was observed that individuals affected with HS typically consult with an average of three or more physicians and get a minimum of three incorrect diagnoses prior to receiving an accurate diagnosis of HS, which is most frequently made by a dermatologist.[29,30] In recent survey, only 23.7% primary care physicians reported feeling confident in diagnosing HS.[31] Both physicians and patients educate themselves on the Internet.[32] The availability of professional literature on HS in non-dermatology journals is limited.[33] Doctors commonly utilize online materials intended for the public to make clinical decisions.[32] It seems reasonable to assume that low readability of online materials dedicated to HS make the diagnostic process of HS more time-consuming and laborious. Information seeking doctors could be distracted and deterred by low comprehensibility of online materials. Failure to obtain the necessary information could result in a prolonged delay in making a diagnosis. Patients who seek to educate themselves on their symptoms could encounter difficulties in understanding online resources that lack clarity and coherence. The age of the Internet led patients to search for information about their symptoms and compare their own diagnosis with the medical knowledge of their doctor during a face-to-face appointment. Patients' remarks and arguments during appointments can

help guide the physician towards the correct diagnosis. Consequently, it could be concluded that the lack of readable HS online resources may impact the timeliness of HS diagnosis. Due to progressive nature of HS, timely diagnosis is paramount.[34] Even short delays in a diagnosis lead to irreversible scarring.[28]

HS was associated with smoking, obesity, and other risk factors for cardiovascular disease.[35,36] Many experts consider HS to be a systematic inflammatory disease because of its associations with inflammatory bowel disease (IBD), axial spondyloarthropathy and autoinflammatory syndromes.[35] Cutaneous IBD – Crohn's disease, was identified as an important differential diagnosis of HS.[37] All of these make the HS a disease that requires complex diagnostic and behavioral interventions. Despite the positive impact of smoking cessation and weight loss on clinical outcomes in patients with HS,[35,36] these interventions require the patient's cooperation. Colonoscopy is recommended to rule out Crohn's disease.[38] Lack of understanding about the disease could make patients reluctant to undergo this intimate and invasive procedure. Similarly, HS management involves long term pharmacological treatment, surgical procedures and the full resolution of the disease could not be guaranteed.[35,36] This require patient's patience and compliance, what is hard to ensure without proper education. All of these, underscore an overwhelming need in improvement of online materials readability dedicated to HS.

Similar results were presented for other dermatological diseases, such as psoriasis, urticaria and rosacea.[39–41] In this new era of immunomodulators in dermatology, it is crucial to ensure easily accessible and comprehensive online resources for patient education.[39–41] Internet resources became a backstage factor in making successful shared therapeutic decisions between physicians and patients. The HS patients are not exempt. Dermatologist should take actions to ensure readable online materials for the HS patients. In the present study, no source was associated with better readability. Other studies revealed that web pages written by the dermatologist were more comprehensive and medically accurate than others.[13,14] A potential solution could be to share medically validated materials from reputable dermatology institutions, including clinics and non-profit organizations, that are accessible and easy to understand. The authors identified only one such action undertaken by the HS tertiary referral center.[42] Despite being clear, accurate, and free of barriers, the material's low placement on the Google search results list made it hard to find. Web promotion is available through the Google search engine.[43] By promoting a website, it gains visibility and is more likely to be clicked on by users as it appears at the top of search results list.[36] Promotion of verified comprehensible materials that are attractive for the Internet users could be a potential solution. Top-searched materials could resolve doubts of patients with HS and then lead to satisfying diagnostic and therapeutic outcomes.

Present study had following limitations. First, Lix score was originally designed to evaluate comprehensibility of newspaper articles in Swedish.[27] Although it was validated on various languages as reliable measure of readability (Swedish, Spanish, Portuguese, Italian, French, Finnish, German, English, Danish),[26,27,44,45] no studies that evaluated Lix in other included languages were found. However, Lix is recognized by scientific community as reliable readability measure for all European languages.[17,26,27] It could be not also excluded, that different readability thresholds would be suitable for other included languages. The results of a Google search may fluctuate depending on the location and date of the search.[25] The study was performed in Poland and Google search results were evaluated between 23 January 2024 and 31 January 2024. Selection of Google as the search engine could also bias the results. Google promotes certain materials due to commercial reason. Top positions of the articles could be not only related to user's interest. As a result, inclusion of the first 50 articles could lead to some bias. Despite their role as sources of information for patients, advertisements and other social media platforms were not included in the study. Quality of the included articles was not evaluated. This was outside the intended scope of study, but it is a potential area for further research.

Conclusion

The Internet ensures plenty of barrier free online materials related to HS. The readability of the presented information was revealed to be very low. The absence of easily comprehensible HS information on the Internet can contribute to delayed diagnosis, which is a lengthy process by itself. Diagnostic, management, and treatment of HS rely on patient's cooperation, compliance, and patience. Without proper educational materials this could be difficult to achieve. Presented finding suggested a great need for dermatologist involvement in creation of comprehensible, multilingual online information for patients and medical professionals about HS. Optimizing the Google search engine for these websites

could be favorable. The significant number of hits for HS-related search terms further emphasizes the importance of this topic for the public.

Data Sharing Statement

The datasets generated and analyzed in the current study are available from the corresponding author upon reasonable request.

Ethics Approval and Informed Consent

The study did not involve any animals or animal-based materials. Human participants and their materials and data were also not involved in this study. The utilization of Internet data alone made ethical approval unnecessary. Informed consents from patients were not applicable.

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Disclosure

Jacek C. Szepietowski has served as an advisor for AbbVie, LEO Pharma, Menlo Therapeutics, Novartis, Pierre Fabre, Sienna Biopharmaceuticals, and Trevi; has received speaker honoraria from AbbVie, Eli Lilly, Janssen, LEO Pharma, Novartis, Sanofi-Genzyme, Sun Pharma, and Berlin-Chemie Mennarini; has served as an investigator; and has received funding from AbbVie, Amgen, Galapagos, Holm, Incyte Corporation, InflaRX, Janssen, Menlo Therapeutics, Merck, Boehringer Ingelheim, Novartis, Almirall, Pfizer, Regeneron, Trevi, and UCB. Other authors report no conflicts of interest in this work.

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6. ARTYKUŁ TRZECI

Deciphering the enigma of itch sensation: insights and impact from a readability study

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Original Article

Deciphering the enigma of itch sensation: insights and impact from a readability study

Tomasz Skrzypczak,[1] Anna Skrzypczak,[2] and Jacek C. Szepietowski,[3]

[1]University Hospital in Wroclaw, Wroclaw, Poland, [2]Faculty of Dentistry, Wroclaw Medical University, Wroclaw, Poland; and [3]Department of Dermatology, Venerology and Allergology, Wroclaw Medical University, Wroclaw, Poland

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Itch; itching; prurigo; readability; terminology.

Correspondence
Jacek C. Szepietowski
Department of Dermatology, Venerology and Allergology
Wroclaw Medical University
Chalubinskiego 1
Wroclaw 50-368
Poland
E-mail: jacek.szepietowski@umw.edu.pl

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Abstract

Background Itch terminology is ambiguous. How itch was described in online materials and how terminology influenced the readability of these materials was previously unknown.
Materials and methods Two groups of search terms, itch and prurigo, were translated into five of the most prevalent European Union (EU) languages. The itch group consisted of "itch" and "pruritus." The prurigo group consisted of "prurigo," "prurigo nodularis," and "chronic prurigo". Then, a search of the terms in each language was queried in the Google search engine in the private mode of the Internet browser. The first 50 results generated were assessed for suitability. Patient education was the primary objective of the materials provided, with no barriers or advertisements included. In cases where the terms yielded identical outcomes, any duplicated materials were omitted from the analysis. When translating search terms within a group led to just one shared transcription, the results were attributed to the search term with the most similar syntax. The Lix score was utilized to assess readability.
Results 314 articles in English, German, Italian, French, and Spanish were evaluated. The term "pruritus" was the most commonly used description for the sensation of itching, with 142 (45%) articles included. Overall, the mean Lix score was 54 $\pm$ 9, classifying all articles as hard to comprehend. Articles in the itch group had significantly ($P < 0.001$) lower mean Lix score (52 $\pm$ 9) than materials in the prurigo group (56 $\pm$ 10).
Conclusions Despite being more accessible to conceptualize, skin conditions such as prurigo had lower readability compared to information about the itch itself. The distinction between "itch" and "pruritus" was unclear.

Introduction

Itch is a significant part of nociception and an essential symptom of skin and systemic diseases.[1] The lack of precise and effective investigative methods in humans and the inadequacy of animal models hindered progress in comprehending its neuropathophysiological and molecular foundation.[1] In addition to the physical and biological origins of itch, its naming convention

remains somewhat elusive. The original description of itch, presented by *Hafenreffer* in 1660, incorporated the term "pruritus" as a synonym.[2] This term continuously appears, usually at the beginning of manuscripts.[2] The word "prurigo" in Latin translates to itch.[3] In dermatology, this term refers to a group of skin conditions characterized by itching and specific skin lesions.[3] "Prurigo" is not commonly used in contemporary American terminology.[3] Apart from "prurigo nodularis," textbooks seldom mention this term.[3] No other category of illnesses has so many synonyms, classification issues, and ambiguity surrounding their meaning.[3] As a result, various illnesses are grouped under the term "prurigo," which translates to itching.[3]

According to a recent study conducted in 13 European countries, 54.3% of dermatology patients reported itch, with 36.9% describing it as a chronic symptom.[4] It was discovered that 8% of individuals with healthy skin experienced itch at the time of investigations, while chronic itch was reported for 4.7% of controls.[4] Itch is not necessarily linked to a dermatologic or systemic problem.[1] The reason for it could be solely idiopathic.[1] The negative impact of itch drives individuals to seek aid from multiple specialists.[1] Patients are motivated to seek information and remedies on their own when they experience unpleasant sensations.[3] As a result, online resources that grant them the ability to acquire specific information instantly seem to be a tempting alternative. A notable 67% of Internet users consider online health information a critical factor in the decision-making process and emphasize the importance of information found on the Internet.[5] It seems reasonable to assume that the readability of online information is crucial in understanding diseases by those who suffer from itch.

The main aim of this study was to investigate how online resources describe itch. The terminology describing itch is diverse across the scientific literature. No data were found for online educational materials. The secondary aim was to evaluate the readability of itch-related articles. To date, there has been no study that assessed the comprehensiveness of itch-related online health information. Finally, the correlation between the abundance of articles and their readability was examined.

Materials and methods

Study groups and search method

The current research was conducted with two study groups: itch and prurigo. Itch consisted of the search terms "itch" and "pruritus." The terms "prurigo," "prurigo nodularis," and "chronic prurigo" were included in the prurigo group. Each search term was translated into the five most utilized languages in the European Union (EU) to ensure representative results. Google Translate and Wikipedia were used to generate translations for these terms. When the searched term could not be found in a Wikipedia article in the desired language, Google Translate was employed as an alternative. A new session of the Google search engine was launched within the web browser's private mode. The language for Google Services was arranged to match the queried term's language, guaranteeing that the search results were in the same language as the term. A search results list was obtained by querying each term during the new Google search session. In cases where the translation of search terms within a group resulted in a single shared transcription, the corresponding results were attributed to the search term with the most significant similarity in syntax. Duplicates were excluded from the results if the search terms yielded identical outcomes. Each language was searched for a particular term, and the first 50 results were collected and studied. It was verified through previous research that most internet users do not read more than the initial 50 hits.[6] Disease-related articles aimed at educating patients and being accessible to the public were included in the collection. The analysis did not consider results not in the searched term's language or those restricted by a password or paywall. Additionally, no scientific articles, videos, personal blogs, online forums, or advertisements were taken into consideration. The classification of a website as an advertisement was based on whether its primary purpose was to promote a specific drug, medical center, or physician rather than educate patients.[7] The analysis did not include articles dedicated to medical professionals, physicians, veterinary medicine, and materials published by regulatory bodies. Five of the most prevalent EU languages by the number of speakers as a percentage of the EU population were included: English, German, French, Italian, and Spanish.[8]

Readability assessment

The Lix readability measure, a validated tool, was used to evaluate all included materials.[9,10] In contrast to other readability measures, such as the Gunning Fogg Index, Lix was proven to be a dependable measure in multiple languages, including English, French, German, Italian, and Spanish.[7,9,10] After its transfer to Microsoft Word, the text was carefully examined, removing redundant elements such as affiliations, hyperlinks, figures, legends, disclaimers, advertisements, author details, and copyright acknowledgments. The "Save as Plain Text" command was used. The appropriate language for proofreading in Microsoft Word was chosen to address spelling and grammar concerns. Every article was saved as an individual file and copied and pasted into the Lix calculator on https://haubergs.com/rix. The recorded data included the total number of sentences, words, average words per sentence, and Lix score. The *Anderson* scale was employed to interpret the Lix score.[10] Texts with a score lower than 20 were labeled as very easy, while those below 30 were categorized as easy to understand.[10] Texts scoring below 40 were considered a little tricky, below 50 were hard, and below 60 were hard to comprehend.[10]

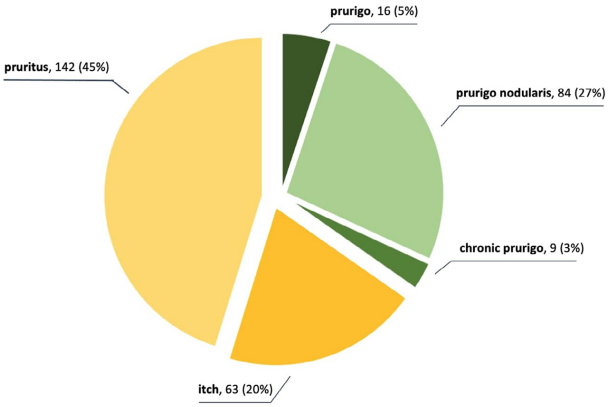

Figure 1 Structure of itch and prurigo groups evaluated in the study. The color yellow refers to the itch group, whereas green refers to the prurigo group. Percentage value was calculated for a total number of included articles (N = 314).

Statistical analyses

The normality of the data was examined with the Shapiro–Wilk test. The Student's *T*-test and *U*-Mann Whitney test were utilized to evaluate differences between the itch and prurigo groups. Differences across search terms and languages were examined using an analysis of variance (ANOVA) or Kruskal–Wallis's test. Univariate linear regression analysis was utilized to investigate the correlation between the mean Lix score of analyzed articles and the number of hits. A P value equal to or less than 0.05 was statistically significant. Microsoft Word and Excel (version 16.59, Redmont, USA) were used to aggregate the data. Statistics were calculated with JASP version 16.59 (JASP Team, University of Amsterdam).

Ethical approval

No animals or animal-derived materials were used in the study. This study did not involve human participants or their materials and data. Owing to the use of Internet data alone, ethical approval was rendered unnecessary.

Results

Prevalence

Overall, 314 articles were included in the study. There were more articles discussing itch than those focused explicitly on prurigo. The itch group contained 205 (65%) articles, while the prurigo group included 109 (35%) articles. When searching for the term "itch" in Italian and French, the translations resulted in words with a comparable syntax to "pruritus." As a result, the term "pruritus" was the most prevalent search term in the itch group and the whole study group. 142 (45%) articles were associated with this term. The least prevalent term was "chronic prurigo," with only 9 (3%) articles. Figure 1 displays the composition of each study group.

Out of all the languages included, only German and Spanish had a higher number of articles related to "itch" compared to "pruritus." Based on this, it is logical to conclude that "pruritus" was the most representative way to describe the feeling of itching. Across all languages included, "prurigo nodularis" was found to be the most frequently used term in the prurigo group. Therefore, it was the most representative word to describe the disease prurigo. Details for each search term and language are shown in Table 1.

Readability

Overall, the mean Lix score was 54 $\pm$ 9, which classified all articles as very hard to comprehend. Articles in the itch group had significantly ($P < 0.001$) lower mean Lix score (52 $\pm$ 9) than materials in the prurigo group (56 $\pm$ 10). Although materials in the itch group were more comprehensible, online articles in both groups were classified as very hard to comprehend. The search term "itch" had a mean Lix score of 49 $\pm$ 7. The use of this search term resulted in articles labeled as hard to comprehend but the most easily understandable out of all the articles assessed. Materials collected with the use of "chronic prurigo" had the highest mean Lix score, 64 $\pm$ 8, and were classified as very hard to comprehend. Except for articles generated with "itch," all materials retrieved using the remaining search terms were classified as very hard to comprehend. The mean Lix score for "itch" (49 $\pm$ 7) was significantly lower than that of "pruritus" (54 $\pm$ 9) within the itch group ($P < 0.001$). The term "prurigo nodularis" had the lowest average Lix score (55 $\pm$ 10) in prurigo group. Significant variations in the mean Lix score were evident across all search terms within the prurigo group

Table 1 Prevalence of included articles and detailed readability metrics for each language and search term

Language	Searched term	No. of articles *n* (%)	Lix score	No. of sentences	No. of words	No. of w/s
English		77 (100%)	47 ± 10	76 ± 54	1172 ± 755	16 ± 6
	Itch	13 (17%)	44 ± 8	69 ± 42	1100 ± 705	16 ± 3
	Pruritus	30 (39%)	47 ± 11	95 ± 69	1431 ± 903	16 ± 7
	Prurigo	1 (1%)	61 ± N/A	37 ± N/A	627 ± N/A	17 ± N/A
	Prurigo nodularis	31 (40%)	49 ± 10	65 ± 34	1031 ± 546	16 ± 6
	Chronic prurigo	2 (3%)	56 ± 4	18 ± 1	235 ± 35	13 ± 1
German		50 (100%)	55 ± 7	82 ± 95	1081 ± 1176	14 ± 3
	Juckreiz	19 (28%)	50 ± 7	121 ± 145	1582 ± 1796	13 ± 2
	Pruritus	12 (24%)	57 ± 5	64 ± 41	845 ± 493	14 ± 2
	Prurigo	2 (4%)	63 ± 11	14 ± 17	196 ± 216	17 ± 6
	Prurigo nodularis	14 (28%)	56 ± 4	57 ± 27	770 ± 352	14 ± 3
	Chronische prurigo	3 (6%)	60 ± 1	95 ± 54	1219 ± 424	14 ± 4
Italian		54 (100%)	62 ± 7	45 ± 38	923 ± 677	22 ± 5
	Prurito	39 (72%)	60 ± 7	54 ± 41	1043 ± 739	21 ± 5
	Prurigo	1 (2%)	61 ± N/A	13 ± N/A	170 ± N/A	13 ± N/A
	Prurigo nodularis	13 (24%)	65 ± 7	25 ± 11	643 ± 336	25 ± 6
	Prurigo cronico	1 (2%)	73 ± N/A	27 ± N/A	658 ± N/A	24 ± N/A
French		56 (100%)	56 ± 7	51 ± 39	892 ± 651	19 ± 5
	Prurit	31 (55%)	54 ± 6	65 ± 41	1139 ± 711	19 ± 5
	Prurigo	9 (16%)	59 ± 9	39 ± 29	624 ± 426	19 ± 6
	Prurigo nodulaire	13 (23%)	55 ± 6	37 ± 29	610 ± 427	17 ± 5
	Prurigo chronique	3 (5%)	71 ± 4	13 ± 4	352 ± 117	28 ± 1
Spanish		77 (100%)	53 ± 8	56 ± 49	1031 ± 866	20 ± 6
	Picazón	31 (40%)	50 ± 7	69 ± 50	1254 ± 934	19 ± 6
	Prurito	30 (39%)	53 ± 7	57 ± 45	1018 ± 862	19 ± 5
	Prurigo	3 (4%)	52 ± 13	24 ± 17	383 ± 231	18 ± 7
	Prúrigo nodular	13 (17%)	61 ± 6	28 ± 24	681 ± 630	24 ± 5
	Prurigo crónico	0 (0%)	N/A	N/A	N/A	N/A

Data were presented as mean ± SD. N/A, not available; w/s, words in one sentence. Percentage values were calculated as percentage of articles for each language. In total, 314 articles were included. Differences across all languages were statistically significant for average Lix score, number of sentences, and words per sentence (all $P < 0.001$). There were no statistically significant differences in number of words across all languages ($P = 0.307$).

($P = 0.021$). Figure 2 thoroughly shows the average readability score for each searched term in both groups.

For articles in the prurigo group, a significantly lower number of words (749 ± 500) and sentences (45 ± 33) per material was found than in the itch group (1,180 ± 937 & 72 ± 10, respectively, both $P < 0.001$). There was no statistically significant difference between the groups regarding the average number of words per sentence in the evaluated articles ($P = 0.331$).

Out of all the languages, the articles generated using itch group search terms were the easiest to read. The translations of "itch" in English, German, and Spanish resulted in more understandable materials compared to those associated with the term "pruritus." In the prurigo group, articles obtained with "prurigo nodularis" had the lowest mean Lix scores in 3 out of 5 included languages (English, German & French). Based on the findings, it could be inferred that "itch" articles were the most easily understood, followed by those including "prurigo nodularis" within the prurigo group. Differences in the average number of sentences and the number of words in a sentence per article were statistically significant across all languages (both $P < 0.001$). There was no statistically significant difference in the number of words across all languages ($P = 0.307$). Table 1 displays the average Lix scores for each searched term across all languages.

Prevalence and readability

Univariate linear regression was conducted to examine the correlation between the readability of online materials and the number of Google search hits. No significant correlation was revealed ($R^2 = -0.234$, $P = 0.656$).

Discussion

Despite being easier to conceptualize, skin conditions that cause itching had lower readability compared to information about the itch itself. Furthermore, online resources focused solely on skin conditions that result in itching had a lower prevalence than itch. Prurigo refers to a group of skin conditions characterized by itching and specific types of skin lesions, such as papules/nodules, that are easily visible to the patients.[3] Although prurigo could be visualized, comprehending articles

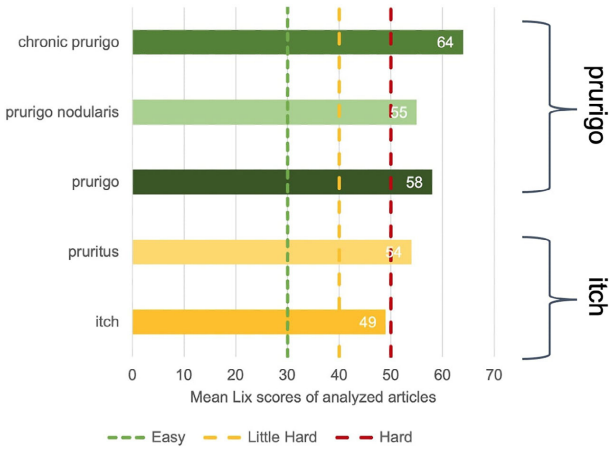

Figure 2 Mean Lix scores of the included search terms. Data were presented as mean. The green color refers to the prurigo group. Yellow indicates the itch group. All differences in mean Lix score between searched terms were statistically significant ($P < 0.001$). Lix score <30 classified text as easy, <40 classified text as little hard, and score <50 classified text as hard to comprehend

about it was more challenging than experiencing the sensation of itching. It was contrary to other studies where visual symptoms proved to be beneficial in patients' understanding.[11–13] Prurigo has a significantly lower prevalence in the European population than itching.[4,14,15] The authors of online materials may be less interested in creating articles dedicated to a smaller population of patients. This could potentially explain the difference in the number of articles in the itch and prurigo groups.

Although it is prevalent, itch was always very hard to describe.[16] Some authors defined "itch" as "an uneasy sensation of the skin that inclines the person to scratch the part affected.".[17] It was thought that "pruritus" was more clinically relevant and was defined as "generalized itching in the absence of primary skin disease."[17] The "itch" translations in French and Italian closely resembled the syntax of "pruritus," leading to the inclusion of reviewed articles in the count for "pruritus." Through everyday use, the boundary between both terms became increasingly vague. Although "pruritus" was more widespread, "itch" proved to be more easily understood. The contrast between these two terms was not apparent. According to expert opinions, it could be assumed that the two terms are interchangeable and have equal significance.[16]

The concept of prurigo was utilized in dermatology for many years without a defined explanation.[18] With the wide variety of ways that prurigo conditions could present, there is a multitude of terms used to describe them.[19] Despite efforts by dermatologic experts to standardize prurigo terminology, "prurigo nodularis" remained the most used term for describing this condition.[3,18] The present investigation yielded coincidental outcomes. The search term "prurigo nodularis" provided the most representative description of prurigo and was linked to the most comprehensible resources. The condition known as chronic prurigo was officially identified as a separate disease within the prurigo group by the consensus of experts in 2018.[18] This term is relatively new and still unfamiliar to most people. The readability of the articles regarding chronic prurigo was low, which could be attributed to their reliance on scientific research. These could all be reasons for the limited number and readability of articles associated with the term "chronic prurigo."

Despite the availability of online articles discussing itch-related diseases, the clarity of these materials was not ideal. Overall, articles in both groups were classified as very hard to comprehend. This corresponded to college graduate level.[20] In the European Union (EU), only 31.8% of citizens completed tertiary education.[21] Therefore, the EU population's comprehension of online content dedicated to these diseases was restricted to less than one-third.

The findings presented also demonstrated that quantity did not necessarily equal readability. In accordance with other studies,[7,22] there was no correlation between the number of hits and the average Lix scores.

Depending on the location and time of the search, the Google results may change dynamically. Poland was the location for this study. The Google search results were generated and reviewed between the dates of February 8, 2024, and February 14, 2024. It cannot be excluded that conducting data collection in another country could result in different outcomes. A collection of articles in five of the most prevalent EU languages could not represent the whole spectrum of online materials dedicated to the EU public. The inclusion of more languages could bring different results.

The initial purpose of Lix was to assess the readability of Swedish newspaper articles.[10] This measure of readability was tested and proven valid in various languages.[9,10,23,24] Despite being considered a reliable measure of readability by the scientific community,[9,10] it could not be ruled out that specific readability thresholds for each language would be more suitable.

Apart from the feeling of itching, prurigo demonstrates papules/nodules, which are easily visible. These should aid patients in understanding their disease. Despite being easier to conceptualize, prurigo-related materials had lower readability than information about the itch. Furthermore, online resources focused on prurigo had a lower prevalence than those related to itch. Dermatologists should be more thorough while explaining prurigo to patients, especially since the number of online materials and their comprehensibility were limited. This should provide better therapeutic outcomes. The terms "itch" and "pruritus" were not clearly distinguished and could be used interchangeably. The continuous evolution of the languages rendered these terms indistinct. We consider that dermatologists should take action to unify itch terminology. The search term "prurigo nodularis" provided the most representative description of prurigo and was linked to the most comprehensible resources. The scarce number and readability of articles dedicated to chronic prurigo implied that recent advances in prurigo classification remain unknown. Dermatologic associations should be called to spread knowledge about new subtypes of prurigo. Itch and prurigo-related online information was not comprehensible for more than one-third of the EU population. Online resources became a standard in facilitating shared decision processes between patients and physicians. Dermatologists should take action to ensure that patients can find readable itch-related information on the Internet. The quantity of the reviewed materials was not correlated with their readability. Few highly readable online materials dedicated to itch-related diseases, positioned at the top of search lists, could ensure a better patient understanding of itch.

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7. STRESZCZENIE W JĘZYKU POLSKIM

Rozprawa doktorska oparta jest o cykl trzech monotematycznych artykułów opublikowanych w międzynarodowych czasopismach naukowych indeksowanych w bazie PubMed, uwzględnionych na liście Journal Citation Reports i znajdujących się w wykazie czasopism naukowych Ministerstwa Nauki i Szkolnictwa Wyższego (MNiSW). Artykuły wchodzące w skład rozprawy doktorskiej zostały opublikowane w czasopismach o łącznym współczynniku wpływu (Impact Factor - IF) 9,3 oraz punktacji MNiSW wynoszącej 270 punktów.

Świąd dotyka znacznej liczby pacjentów, szczególnie tych z chorobami skóry, takimi jak świerzbiączka, atopowe zapalenie skóry (AZS) i trądzik odwrócony (HS), negatywnie wpływając na ich jakość życia. Uciążliwe i nieprzyjemne objawy skłaniają chorych do szukania pomocy w każdym możliwym miejscu. Internet stał się kluczowym źródłem informacji dla pacjentów, jednak czytelność ogólnodostępnych artykułów dotyczących tych chorób jest bardzo słabo znana.

Wszystkie trzy artykuły z cyklu opierały się na podobnej metodologii. Słowa klucze zostały przetłumaczone na wybrane języki krajów UE (Unii Europejskiej) i wyszukiwane w Google. Wyszukiwanie odbywało się każdorazowo w nowej sesji trybu prywatnego przeglądarki, zgodnie z zaleceniami firmy Google (Google LLC, Mountain View, USA) dotyczącymi wyszukiwania w językach obcych. W pierwszym artykule słowem klucz był „atopic dermatitis", w drugim były „hidradenitis suppurativa i „acne inversa", a w trzecim wykorzystano dwie grupy słów kluczy: *itch* i *prurigo*. W grupie *itch* znajdowały się „itch" i „pruritus", a w grupie *prurigo*: „prurigo", „prurigo nodularis" i „chronic prurigo". W pierwszych dwóch artykułach słowa klucze były tłumaczone na 23 oficjalne języki UE. W trzecim artykule słowa klucze z dwóch grup były tłumaczone na 5 najbardziej powszechnych języków UE. W każdej sesji generowana była lista wyników, w której pierwsze 50 pozycji było oceniane pod kątem stosowności. Wykluczono materiały niedostępne bezpłatnie, zdublowane, w innym języku niż wyszukiwana fraza oraz materiały reklamowe, dotyczące medycyny alternatywnej, weterynarii i przeznaczone dla zawodów medycznych. W drugiej i trzeciej pracy z cyklu, gdy różne szukane frazy prowadziły do tych samych artykułów, powielone materiały nie były uwzględniane w badaniach. Dodatkowo wszystkie artykułu naukowe, widea, blogi osobiste, fora online i reklamy nie zostały włączone do analiz. We wszystkich trzech pracach z cyklu, czytelność artykułów była oceniana przy użyciu wskaźnika LIX.

W całym cyklu prac przeanalizowano łącznie 1387 artykułów, z czego 615 dotyczyło AZS, 458 HS, a 314 odnosiło się do świądu i świerzbiączki. Do badań zakwalifikowano 306 artykułów znalezionych przy użyciu „hidradenitis suppurativa" i 152 z „acne inversa". Przy użyciu słów kluczy z grupy *itch* zakwalifikowano 63 artykuły znalezione przez wyszukiwanie słowa „itch" i 142 przy użyciu „pruritus". W grupie *prurigo* 84 artykuły zostały włączone dla „prurigo nodularis", 16 dla „prurigo" i 9 dla „chronic prurigo". Ogólna wartość wskaźnika LIX dla materiałów poświęconych AZS wynosiła 56 ± 8, dla HS 57 ± 9, a dla świądu i świerzbiączki 54 ± 9, klasyfikując je jako bardzo trudne do zrozumienia. Nie było statystycznie istotnej różnicy wartości wskaźnika LIX między artykułami znalezionymi przy użyciu "hidradenitis suppurativa" i "acne inversa". Artykuły z grupy *itch* miały znacząco niższy wskaźnik LIX (52 ± 9) niż z grupy *prurigo* (56 ± 10, $P < 0.001$). W grupie *itch* artykuły znalezione przy użyciu "itch" miały niższy wskaźnik LIX (49 ± 7) niż z "pruritus" (54 ± 9, $P < 0.001$). W grupie *prurigo* artykuły znalezione przy użyciu "chronic prurigo" miały najwyższy wskaźnik LIX (64 ± 8), a z "prurigo nodularis" najniższy (55 ± 10, $P = 0.021$). Artykuły w językach angielskim, niderlandzkim i szwedzkim miały najniższe wskaźniki LIX i były najłatwiejsze do zrozumienia. Wartości wskaźnika LIX dla artykułów w innych językach przekraczały 50 punktów, klasyfikując je jako bardzo trudne do zrozumienia.

Ogólnodostępne artykuły online poświęcone schorzeniom dermatologicznym, takim jak AZS, HS, świąd i świerzbiączka są dla czytelników bardzo trudne do zrozumienia. W przypadku świądu, może to wynikać z różnic w używanych terminach. Teksty napisane w językach angielskim, niderlandzkim i szwedzkim są najbardziej zrozumiałe. Poziom czytelności najprawdopodobniej nie zależy od źródła artykułu. Mimo, że dostępność nieprofesjonalnych artykułów online dotyczących chorób skóry jest szeroka, ich zrozumienie stanowi wyzwanie dla wielu osób.

8. STRESZCZENIE W JĘZYKU ANGIELSKIM

The doctoral thesis is based on a series of three monothematic articles published in international scientific journals indexed in the PubMed database, included in the Journal Citation Report list, and listed in the Ministry of Science and Higher Education (MNiSW) list of scientific journals. The articles included in the doctoral thesis were published in journals with combined Impact Factor (IF) of 9.3 and MNiSW score of 270 points.

Itch affects a significant number of patients, especially those with skin diseases such as prurigo, atopic dermatitis (AD) and hidradenitis suppurativa (HS), negatively impacting their quality of life. Troublesome and unpleasant symptoms drive patients to seek help wherever possible. The Internet has become a crucial source of information for patients, yet the readability of publicly available articles on dermatologic diseases is poorly understood.

All three articles in the series were based on similar methodology. Keywords were translated into selected languages of EU (European Union) countries and searched on Google. Each search was conducted in a new session of private browsing mode, following Google (Google LLC, Mountain View, USA) recommendations for searching in foreign languages. In the first article, the keyword was “atopic dermatitis” in the second were “hidradenitis suppurativa” and “acne inversa” and in the third two sets of keywords were used: *itch* group and *prurigo* group. In the *itch* group, “itch” and “pruritus”, and in the *prurigo* group “prurigo”, “prurigo nodularis” and “chronic prurigo” were used. In the first and second article of the series, keywords were translated into 23 official EU languages. In the third article, keywords from two groups were translated into the five most common EU languages. Each session generated a list of results, with the first 50 items evaluated for relevance. Materials that were not freely available, duplicated, in a language other than the searched phrase or related to advertising, alternative medicine, veterinary medicine or intended for medical professionals were excluded. In the second and third article of the series, when different search phrases led to the same articles, duplicated materials were not included in the analysis. Additionally, all scientific articles, videos, personal blogs, online forums, and advertisements were excluded from the analysis. In all three articles of the series, the readability of the articles was evaluated using the LIX indicator.

Throughout the series of studies, a total of 1387 articles were analyzed, of which 615 were related to AD, 458 to HS, and 314 to itch and prurigo. For the study, 306 articles found using “hidradenitis suppurativa” and 152 using “acne inversa” were included. Using keywords from the *itch* group, 63 articles were qualified using "itch" and 142 using "pruritus." In the *prurigo*

group, 84 articles were included for "prurigo nodularis," 16 for "prurigo," and 9 for "chronic prurigo." The overall LIX value for materials related to AD was 56 ± 8, for HS 57 ± 9, and for itch and prurigo 54 ± 9, classifying them as very difficult to understand. There was no statistically significant difference in LIX values between articles found using "hidradenitis suppurativa" and "acne inversa." Articles from the *itch* group had a significantly lower LIX values (52 ± 9) than those from the *prurigo* group (56 ± 10, $P < 0.001$). In the itch group, articles found using "itch" had a lower LIX values (49 ± 7) than those using "pruritus" (54 ± 9, $P < 0.001$). In the *prurigo* group, articles found using "chronic prurigo" had the highest LIX values (64 ± 8), while those using "prurigo nodularis" had the lowest (55 ± 10, $P = 0.021$). Articles in English, Dutch, and Swedish had the lowest LIX values and were the easiest to understand. LIX values for articles in other languages exceeded 50 points, classifying them as very difficult to understand.

Publicly available online articles dedicated to dermatological disorders such as AD, HS, itch, and prurigo are very difficult for readers to understand. In the case of itch, this could be due to differences in terminology used. Texts written in English, Dutch, and Swedish are the most understandable. The level of readability potentially does not depend on the source of the article. Although the availability of unprofessional online articles on skin diseases is broad, understanding them poses a challenge for most individuals.

9. ETYKA

Wrocław, dnia 18 marca 2024r

Tomasz Skrzypczak
ul. Antoniego Wiwulskiego 14/1
51-629 Wrocław
tel. 669890020
t.skrzypczak.pl@gmail.com

Oświadczenie

Oświadczam, że nie jest wymagana zgoda odpowiedniej komisji bioetycznej na prowadzenie badań będących przedmiotem mojej pracy doktorskiej.

Temat pracy: *Holistyczna analiza poziomu czytelności ogólnodostępnych artykułów on-line dotyczących wybranych schorzeń dermatologicznych*

.....
podpis

.....
podpis proponowanego promotora

10. CURRICULUM VITAE

Tomasz Skrzypczak

Data i miejsce urodzenia:
22.11.1997 Leszno

t.skrzypczak.pl@gmail.com
tel. 669890020
https://orcid.org/0000-0003-4030-9101

Wykształcenie:

Lekarz – *lipiec 2023*	Uniwersytet Medyczny im. Piastów Śląskich we Wrocławiu, Wydział Lekarski, kierunek lekarski

Doświadczenie zawodowe:

• *październik 2023 – teraz* lekarz stażysta	Uniwersytecki Szpital Kliniczny we Wrocławiu, ul. Borowska 2013, 55-556 Wrocław
• *marzec 2024 – teraz* pracownik dydaktyczny (zajęcia zlecone)	Katedra Fizjologii i Patofizjologii, Uniwersytet Medyczny im. Piastów Śląskich we Wrocławiu

Osiągnięcia:

• *wrzesień 2020* nagroda specjalna	Projekt „*Interdyscyplinarny projekt Coro AI – inteligentny stetoskop*” – XXVI Forum Teleinformatyki, Forum Młodych Mistrzów
• *grudzień 2020* finalista	"*Level Up - Wielka Bitwa o Startup*". Dolnośląski Fundusz Rozwoju

Certyfikaty:

• *wrzesień 2019* USMLE Step 1	The United States Medical Licensing Examination (USMLE), the National Board of Medical Examiners (NBME), Philadelphia, USA

- *maj 2022*

  USMLE Step 2CK

  The United States Medical Licensing Examination (USMLE), the National Board of Medical Examiners (NBME), Philadelphia, USA

Konferencje:

- *marzec 2020*

  uczestnik

  BAPRAS, 18th Undergraduate Day 2020, Birmingham, UK

- *grudzień 2020*

  poster

  „Inteligentny Stetoskop – Diagnostyka chorób serca przy użyciu metod analizy sygnałów i uczenia maszynowego”, Ogólnopolska Matematyczna Konferencja Studentów OMatKo! 5-6 grudnia 2020, Wrocław

Naukowe:

Publikacje (poza cyklem):

- 10 pełnotekstowych artykułów opublikowanych w międzynarodowych czasopismach indeksowanych w bazie PubMed, z czego 8 jako pierwszy autor.
- Całkowity współczynnik wpływu (Impact Factor) opublikowanych prac = 16.0
- Punktacja ministerialna: 430 punktów

Nagrody:

- Wielokrotne stypendia rektora dla najlepszych studentów

11. DOROBEK NAUKOWY

Publikacje w międzynarodowych czasopismach z wyłączeniem prac stanowiących cykl publikacji do Rozprawy Doktorskiej:

1. **Skrzypczak T**, Mamak M.: *Assessing the Readability of Online Health Information for Colonoscopy - Analysis of Articles in 22 European Languages.* J Cancer Educ. 2023 Dec;38(6):1865-1870.
   doi: 10.1007/s13187-023-02344-2.
   PMID: 37493981
   IF: 1,6 ; Punktacja Ministerialna: 70

2. **Skrzypczak T**, Skrzypczak A, Skrzypczak M.: *Implications of Public Interest in Colonoscopy: Analysis of Google Trends Data From 12 European Countries.* Cureus. 2023 Jul 24;15(7):e42395.
   doi: 10.7759/cureus.42395.
   PMID: 37621831.
   IF: 1,2 ; Punktacja Ministerialna: 20

3. Chłopowiec AR, Karanowski K, **Skrzypczak T**, Grzesiuk M, Chłopowiec AB, Tabakov M.: *Counteracting Data Bias and Class Imbalance-Towards a Useful and Reliable Retinal Disease Recognition System*. Diagnostics (Basel). 2023 May 29;13(11):1904.
   doi: 10.3390/diagnostics13111904.
   PMID: 37296756
   IF: 3,6 ; Punktacja Ministerialna: 70

4. **Skrzypczak T**, Skrzypczak A, Skrzypczak M: *Publication Times and Impact Factors (IFs) in Dentistry Journals.* Cureus. 2022 Dec 19;14(12):e32680.
   doi: 10.7759/cureus.32680.
   PMID: 36660527
   IF: 1,2 ; Punktacja Ministerialna: 20

5. **Skrzypczak T**, Skrzypczak A, Michałowicz J: *The Relationship Between Iron Status and Atherosclerotic Cardiovascular Disease Risk in Non-anemic Patients Without a History of Cardiovascular Diseases: A Cross-Sectional Study.* Cureus. 2022 Sep 22;14(9):e29439.
   doi: 10.7759/cureus.29439.
   PMID: 36312608
   IF: 1,2 ; Punktacja Ministerialna: 20

6. **Skrzypczak T**, Jany A, Michałowicz J, Hossa M, Bogusławska J, Targonska M: *Public Interest in Cataract Surgery: Analysis and Implications of Google Trends Data from 14 European Countries*. Ophthalmic Epidemiol. 2022 Feb;29(1):108-115.
   doi: 10.1080/09286586.2021.1904513.
   PMID: 33789529
   IF: 1,8 ; Punktacja Ministerialna: 70

7. Tkaczyszyn M, **Skrzypczak T**, Michałowicz J, Ponikowski P, Jankowska EA: *Iron deficiency as an emerging therapeutic target in patients stabilized after an episode of acute heart failure*. Cardiol J. 2021;28(6):962-969.
   doi: 10.5603/CJ.a2021.0165.
   PMID: 34897633
   IF: 3,0 ; Punktacja Ministerialna: 100

8. **Skrzypczak T**, Błachnio K, Górnicki T, Kmieć J, Ciąder A, Biernikiewicz M, Majchrowska M, Sobieszczańska M, Szymala-Pędzik M, Kałka D: *Association between the Desire for Breast Augmentation and Instagram Engagement: A Cross-Sectional Survey among Young Polish Women.* Int J Environ Res Public Health. 2021 Sep 30;18(19):10317.
   doi: 10.3390/ijerph181910317.
   PMID: 34639616
   Punktacja Ministerialna: 20

9. **Skrzypczak T**, Michałowicz J, Hossa M, Mamak M, Jany A, Skrzypczak A, Bogusławska J, Kowal-Lange A: *Publication Times in Ophthalmology Journals: The Story of Accepted Manuscripts*. Cureus. 2021 Sep 5;13(9):e17738.
   doi: 10.7759/cureus.17738.
   PMID: 34584811
   IF: 1,2 ; Punktacja Ministerialna: 20

10. **Skrzypczak T**, Jany A, Bugajska-Abramek E, Bogusławska J, Kowal-Lange A: *A Comparative Study of Ranibizumab and Aflibercept for Neovascular Age-Related Macular Degeneration: 12-Month Outcomes of Polish Therapeutic Program in Non-Tertiary Institution.* Cureus. 2021 Jun 25;13(6):e15916.
    doi: 10.7759/cureus.15916.
    PMID: 34336421
    IF: 1,2 ; Punktacja Ministerialna: 20

Sumaryczny Impact Factor (IF): 16,0
Sumaryczna Punktacja Ministerialna: 430 punktów

12. OŚWIADCZENIA WSPÓŁAUTORÓW

UNIWERSYTET MEDYCZNY
IM. PIASTÓW ŚLĄSKICH WE WROCŁAWIU

Wydział Lekarski
Katedra i Klinika Dermatologii, Wenerologii i Alergologii
Kierownik : Prof.dr hab. n.med. Jacek Szepietowski
Ul. Chałubińskiego 1, 50-368 Wrocław
Tel. +4871/327-09-41 Fax. +4871/327-09-42
e-mail: dermwen@umw.edu.pl http://www.derm.umed.wroc.pl

Wrocław, dnia 22.04.2024r

OŚWIADCZENIE

Oświadczam, że w pracy:

Skrzypczak T, Skrzypczak A, Szepietowski JC.: Readability of Patient Electronic Materials for Atopic Dermatitis in 23 Languages: Analysis and Implications for Dermatologists. Dermatol Ther (Heidelb). 2024 Feb 24.doi: 10.1007/s13555-024-01115-1.

Mój udział polegał na zbieraniu danych, pomocy w prowadzeniu badań i korektach edytorskich pierwotnej wersji maszynopisu.

Anna Skrzypczak
.....
(Anna Skrzypczak)

Zatwierdzam

Prof. dr hab. n. med. Jacek Szepietowski
.....
Prof. dr hab. n. med. dr h.c.
Jacek Szepietowski

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.....
(prof. dr hab. Jacek Szepietowski)

Zatwierdzam

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Skrzypczak T, Skrzypczak A, Szepietowski JC.: Hidradenitis Suppurativa Online Documents Readability: An Analysis Including 23 European Languages. Clin Cosmet Investig Dermatol. 2024;17:853-862 https://doi.org/10.2147/CCID.S463861

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Skrzypczak T, Skrzypczak A, Szepietowski JC.: Deciphering the enigma of itch sensation: insights and impact from a readability study. Int J Dermatol. 2024 Apr 5. doi: 10.1111/ijd.17144.

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