Background and aims Systemic lupus erythematosus (SLE) is a complex multi-system autoimmune disorder. Patients frequently access the internet to increase their knowledge about the condition.

We assessed the quality, reliability and readability of online sites relating to SLE.

Methods The search phrase ‘systemic lupus erythematosus’ was used with the three most commonly accessed internet search engines (Google, Bing and Yahoo) to identify websites. The first 25 hits (excluding duplicates and excluded websites) for each search were assessed for quality using the DISCERN instrument (scores 15–80 points), reliability using the JAMA benchmarks (assessing authorship, attribution of references, currency (date of posted content) and disclosure of conflict of interest) and readability using the Gunning-FOG index (ideal score 7–8).

Results There was significant concordance between the hits returned from each search engine with 26 unique websites identified. The average DISCERN score was 47.7 (SD 13.2), and ranged from 19–75. Websites that appeared earlier in searches did not have higher DISCERN scores (Pearson correlation –0.16).

Currency was present in 50.0%, appropriate authorship in 46.2% and attribution of references and disclosure of interest in only 15.4% of websites.

The average readability of the websites was 9.3 (SD 3.4) using the FOG index.

Conclusions The overall quality of online health information relating to SLE is only fair.
Reliability as measured by the JAMA benchmarks was average to poor.

The readability is higher than recommended for the general public, which may limit understanding.

This assessment highlights the need for clinicians to provide patients with alternative sources of high quality information regarding SLE.

Methods

We studied 63 SLE patients (≥4 criteria/ACR) with confirmed history of thrombosis after SLE diagnosis. As controls, 63 SLE patients without thrombosis, matched by age, gender and lupus duration were included. Disease characteristics, medication, traditional risk factors for thrombosis and thrombotic event information were retrieved from clinical files. A blood sample was drawn to determine anti-cardiolipin (IgG/IgM), anti-β2-GP1 (IgG/IgM), LA, anti-RNP/Sm and anti-Sm antibodies. Sensitivity, specificity, positive and negative predictive values (PPV, NPV) and Likelihood Ratios (LR) were calculated.

Results

One hundred and twenty six SLE patients were studied. Cases and controls were similar in age, gender and disease duration (p=NS). There were no differences in the prevalence of traditional risk factor for thrombosis between cases and controls (p=NS). Among patients with thrombosis a higher frequency of anti-RNP/Sm (83% vs 62%, p<0.001), LA (62% vs 19%, p<0.001), aPL triple marker (17% vs 2%, p=0.04) and anti-RNP/Sm+AL combination (52% vs 14%, p<0.001) was observed. The combination of anti-RNP/Sm+AL showed a sensitivity 52%, specificity 86%, PPV 78% and NPV 63%, positive LR 3.67 (IC 95% 1.92–7.04) and negative LR 0.55 (IC 95% 0.42–0.74).

Conclusions

This study confirmed that anti-RNP/Sm+LA association represents a risk factor for thrombosis in SLE patients.