

Title Page

Full Title

Quality and Readability of Online Patient Information Regarding Sclerotherapy for Venous Malformations

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Short title

Online patient information regarding venous malformation sclerotherapy

Keywords

Internet, online, patient information, venous malformation, sclerotherapy, children, Interventional Radiology

1 **Full Title**

2 Quality and Readability of Online Patient Information Regarding Sclerotherapy for Venous Malformations

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1 Manuscript

2 Abstract

3 *Background* Patients commonly utilize the internet as a source of information about their condition and
4 treatments. However, it is unregulated and there is wide variation in information quality.

5 *Objective* This study evaluates the readability and quality of online information for pediatric and adult patients
6 and carers regarding sclerotherapy for venous malformations.

7 *Materials and methods* “Venous malformation sclerotherapy” was entered into Google and search engine results
8 were reviewed until 20 sites which satisfied predefined inclusion criteria were identified. Scientific and non-
9 patient-focused webpages were excluded. Readability was assessed using the Flesch Reading Ease Score
10 (FRES) and American Medical Association (AMA) reading difficulty recommendations and quality was
11 assessed using Journal of the American Medical Association (JAMA) standards and assessing if the site
12 displayed HONcode ('Health on the Net Code') certification. Assessment of breadth of relevant information was
13 made using a predefined checklist.

14 *Results* 49 search engines results were reviewed before 20 sites were identified for analysis. Average FRES
15 was 44 (range 24.2–70.1), representing a ‘fairly difficult’ reading level. None of the sites had a FRES meeting
16 the AMA recommendation of 80-90. Only one site met all 4 JAMA quality criteria (average 2.1). None of the
17 sites displayed a HONcode seal. The information most frequently found was: sclerotherapy is performed by
18 radiologists; multiple treatments may be needed and surgery is an alternative treatment.

19 *Conclusion* Online information regarding sclerotherapy for venous malformations is heterogonous in quality
20 and breadth of information, and does not meet readability recommendations for patient information.
21 Radiologists should be aware of and account for this patient consultations.

22 Keywords

23 Internet, online, patient information, venous malformation, sclerotherapy, children, Interventional Radiology

24

1 **Introduction**

2 Venous malformations are low-flow vascular malformations; they are the most common malformations seen in
3 referral centers but are still rare, occurring in up to one in 5000 births [1]. Venous malformations present with a
4 variable spectrum of symptoms that include pain, bleeding and unsightliness. They are present from birth, and
5 can occur anywhere, particularly in areas of soft tissue [2]. Not all venous malformations require treatment
6 however percutaneous sclerotherapy is widely advocated as the treatment of choice for most venous
7 malformations that require active treatment, usually with the aim of managing the patient's symptoms rather
8 than providing a cure [1]. Intervention is usually only indicated for activity-limiting pain or cosmetic reasons.
9 Information regarding treatment options is delivered by healthcare providers but patients and their families often
10 seek information elsewhere, including the internet [3].

11 The advent of the internet has revolutionized the way in which information is accessed and shared around the
12 world. It is now estimated that over 3.4 billion people use the internet, a figure representing 46.1% of the global
13 population [4]. In developed countries including the United States, United Kingdom, Canada, France and
14 Germany, this percentage climbs to as much as 87% [5]. It has been estimated in some surveys that as many as
15 55% of internet users have performed medical or health-related searches [6], with 8 million Americans seeking
16 health information online every day [7]. Most searches are performed via search engines, as opposed to
17 dedicated medical portals, which may lead to discrepancy in the information patients access, as well as
18 potentially misleading information.

19 Patients with vascular anomalies want to be involved in decision making regarding their treatment [8] and
20 clinicians have a duty of care to ensure that patients have the information they need to do this [9]. It is therefore
21 useful for clinicians to know the nature of information to which patients and their families are exposed outside
22 of the clinic. The purpose of this study therefore was to evaluate the quality, accessibility and readability of sites
23 that patients and their families may read when searching for information about sclerotherapy for venous
24 malformations. Sclerotherapy of venous malformations was chosen because this is a disease for which pediatric
25 radiologists offer a real and lasting benefit over alternative treatment options including decreased morbidity,
26 invasiveness, shorter duration of hospitalization and decreased cost [10].

27 **Materials and Methods**

28 A search for online information regarding sclerotherapy for venous malformations was conducted using one of
29 the most popular free web search engines: Google (Google Inc., California, USA)[11]. The search engine
30 default settings were not changed, all prior search history was deleted, no plug-ins utilized and no advanced
31 search options were used to ensure that there would be no bias or inconsistency in the presentation of sites by
32 the search engine. The search term used was 'venous malformation sclerotherapy'. Initially the search was
33 conducted using the Google web search engine by two authors on separate computers. The search engine results
34 were assessed sequentially in the order listed and the following inclusion criteria were applied: sites must not be
35 a sponsored hyperlink (designated by the term 'Ad'), must not be scientific articles, must be patient-focused,
36 must not present information solely in picture or video format and must be in English. These inclusion criteria

1 were applied until the first 20 sites that satisfied them were identified. This was considered an adequate number
2 for useful analysis because they are likely to include most of the websites that patients and their families may
3 visit [12]. The search was repeated on Yahoo! (Yahoo! Inc., California, USA) and Bing (Microsoft Corporation,
4 Washington, USA) search engines to assess if these alternative commonly used search engines yielded similar
5 results. The 20 sites from the Google web search engine were then analyzed for readability and information
6 quality using the tools described below and summarized in Table 1. Both authors analyzing the websites were
7 medical students and all results and discrepancies were overseen by and discussed with a fellowship trained
8 pediatric interventional radiologist with a special interest in the management of vascular anomalies. 20 sites
9 were analyzed as these are likely to include most of the websites that patients and their families may visit.

10 **Readability**

11 Readability was analyzed using the Flesch Reading Ease Score [13]. This uses word complexity and sentence
12 length to estimate how difficult a given passage of text is to read (Table 1). This is validated as an assessment of
13 readability but not necessarily comprehension. It is free to use and has been widely used to analyze readability
14 in similar studies to this [3, 14]. Scores were generated by copying text and pasting to the measuring tool on
15 Readability-Score.com [15], one of numerous free online automated scoring sites. Scores are presented as a
16 value out of 100, with lower scores indicating a higher reading difficulty.

17 **Quality**

18 Quality of information was assessed in three ways: compliance with the Journal of American medical
19 association benchmarks [16], presence of HONcode seal (the Health on the Net Foundation's certification of
20 quality) [17] and a subjective review of the breadth of information provided on each site.

21 The Journal of the American Medical Association benchmarks signify a set of four core standards designed to
22 represent quality of electronic content. The standards are: authorship (all authors and contributors provided
23 alongside their credentials and affiliations), attribution (all references and/or sources clearly represented with
24 copyright acknowledged), disclosure (website ownership, sponsorship, advertising, underwriting, commercial
25 support and potential conflicts of interest disclosed) and currency (clear listing of dates the content was posted
26 and updated) [16]. Websites were given a score out of four by two authors, with a point given for each standard
27 achieved. Any discrepant scores were discussed with a third expert (pediatric interventional radiologist) and a
28 consensus reached.

29 The HONcode certification is a non-profit, non-governmental system designed to encourage the dissemination
30 of quality healthcare information to both patients and professionals. It is based on a set of eight ethical standards
31 reflecting transparency and, indirectly, the usefulness and objectivity of information on the internet [17]. These
32 standards are: authority (give qualifications of authors), complementarity (information aims to support, not
33 replace doctor-patient relationship), privacy (respect the privacy and confidentiality of personal data submitted
34 to the site by the visitor), attribution (cite sources of information), justifiability (justification of claims),
35 transparency (accessible presentation, provide valid contact details), financial disclosure, advertising (clearly

1 distinguishable advertising from editorial content) [17]. The certification can be requested by any health related
2 or medical website and, following verification of the HONcode's principles by the HONcode committee, the
3 site will gain the right to display the HONcode seal. Each site was assessed for the presence or absence of the
4 HONcode seal.

5 The breadth of information relevant to sclerotherapy for venous malformations particularly that which may help
6 a patient or their family decide upon a course of treatment, was evaluated by assessing whether sites discussed
7 specific, relevant topics outlined in a pre-defined checklist (Table 3). The clinical information checklist was
8 developed based on the authors (pediatric interventional radiologists) expertise in the treatment of vascular
9 anomalies and included information which should be discussed as part of an informed consent conversation
10 including an explanation of the health problem, the proposed procedure including the anticipated post
11 procedural course and its benefits, risks, and alternatives [18]. Two separate authors (medical students) assessed
12 each site using the created checklist and any conflicting scores were discussed with a third expert (pediatric
13 interventional radiologist) and a consensus reached.

14 **Results**

15 29 websites were excluded before 20 sites were identified for analysis. Reasons for exclusion included:
16 scientific articles (n= 26), video or pictorial format (n=2), not patient focused (n=1). 14 of the 20 selected
17 websites were produced by hospitals, universities or clinics, three by professional radiologist groups, one by a
18 private doctor and perhaps surprisingly only two by common information websites (Medscape eMedicine (site
19 4) and Wikipedia (site 7)). Of the 20 sites, 11 appeared on the first two pages of Google, nine on the first two
20 pages of Bing and eight on the first two pages of Yahoo!. Agreement between appearance on the first two pages
21 of these sites was good between Google and Bing and moderate between Google and Yahoo!. 12 of the sites
22 discussed vascular malformations in general, not specifically venous malformations.

23 **Readability**

24 The mean Flesch Reading Ease Score across the 20 sites was 44/100 (range 24.2 – 70.1), representing a 'fairly
25 difficult' or 10/11th grade reading level.

26 **Quality**

27 The mean number of Journal of the American Medical Association benchmarks met by websites was 2.05/4.
28 Only 1 site (5%) met all four criteria, 8 sites (40%) met three criteria, 2 sites (10%) met two criteria and 9 sites
29 (45%) met only one of the criteria. The authorship standard was met by 8 sites (40%), attribution standard by 5
30 sites (25%), disclosure standard by 17 sites (85%) and currency by 11 (55%). None of the websites reviewed
31 displayed an HONcode seal. The breadth of information contained in the sites varied and is shown in Figure 1.
32 The most frequently appearing information was that interventional radiology perform sclerotherapy (17 sites
33 (85%)), sclerotherapy may need multiple treatments (17 sites (85%)) and that surgery is an alternative method

1 of treatment (15 sites (75%)). The mean number of items from the checklist was 8.7 (range 5 – 15). Number of
2 items covered did not correlate with Flesch Reading Ease Score (Pearson's $r=0.1714$).

3 **Discussion**

4 Despite the immense volume of information available on the internet, lack of standardized regulation has
5 allowed for marked variation in the reliability and quality of sites. This is a phenomenon recognized by some
6 internet users; one recent study found that 86% of internet users questioned had expressed concern over the
7 reliability of online health resources [6]. Despite this, millions of people use the internet as a source of health
8 care information [6] and 70% of patients say that information they have found online influences their treatment
9 decisions [19].

10 Readability of sites containing the medical information is important because there is a close correlation between
11 low health literacy levels (decreased ability to understand, retain and interpret information regarding their
12 health) and significantly reduced health outcomes [20]. The National Institute of Health and American Medical
13 Association both recommend that patient-directed health information should be presented at a reading level of
14 no higher than the American sixth-grade level (11-12 years of age) [14, 21]. This equates to a Flesch Reading
15 Ease Score of 80 – 90 [15]. None of the websites analyzed in this study attained a reading ease score that
16 satisfied the American Medical Association and National Institute of Health recommendations. There are many
17 studies across a great range of medical subjects, that suggest that patient information on the internet is well
18 above this level [7, 22–26]. Amongst these studies, the reading level of online health information ranged from
19 the American fourth-grade level to levels above the 12th grade, above the American Medical Association and
20 National Institute of Health recommendations [7, 22–26]. Despite this wide variation, the majority of studies
21 found only several sites to have reading levels below the sixth-grade, with the majority averaging at the 10th
22 grade [7, 22–26]. The mean reading ease score across the 20 sites analyzed in this study was equivalent to the
23 American 10/11th grade reading level. This indicates that online information regarding sclerotherapy for venous
24 malformations is at a similarly difficult reading level to online information for various other conditions. It must
25 be borne in mind however, that readability does not necessarily equate to comprehensibility, which can be
26 enhanced through the use of diagrams and pictures.

27 Using the Journal of the American Medical Association benchmarks as a marker, the quality of the sites
28 reviewed was generally poor with an average of only two of the four benchmarks present. It is interesting that
29 the two most commonly neglected benchmarks were authorship (40%) and attribution (25%) respectively. These
30 criteria predominantly function to demonstrate appropriate scientific process by checking for source referencing
31 and expert contributions and therefore act as reassurance to the reader that the information is accurate. Similarly,
32 the lack of HONcode certification on all the sites may be regarded by readers to be signs of poor quality.
33 However, to display a HONcode seal an explicit and voluntary application to the organization has to be made
34 and certification requires annual revalidation (with the latter requiring a small fee). It may therefore be the case
35 that site owners do not consider application sufficiently cost-effective. Displaying a HONcode seal demonstrates
36 that a site meets the ethical standards, but absence of the seal does not mean that a site does not meet these
37 standards.

1 Guidance from both American Medical Association [27] and the General Medical Council in the UK [9]
2 strongly advocates a collaborative approach by physicians with their patients. A shared decision-making
3 approach to vascular malformation management is valued by patients and their families but is not always
4 practiced [8]. It is vital therefore that patients are provided with the relevant knowledge allowing them to engage
5 fully in their care and to give their informed consent [18]. Information which should be given includes an
6 explanation of the health problem, the proposed procedure including the anticipated post procedural course and
7 its benefits, risks, and alternatives [18]. The clinical information checklist used in this study was designed as an
8 attempt to quantify the breadth of information which may be relevant to informed consent discussions.
9 Collectively, the sites made reference to all items on the checklist, although none did so independently.
10 Treatment strategies for vascular malformations are personalized, depending on lesion morphology, size,
11 location, and associated symptoms [28]. There was marked heterogeneity between sites as to what information
12 was covered and this may reflect the dilemma of providing details that are generalizable to all patients with the
13 condition and the need to keep the information comprehensible. Against this however, there was no correlation
14 between the readability and breadth of information covered.

15 Whilst there is good evidence to support sclerotherapy for venous malformations, the studies are heterogeneous
16 and multiple agents and techniques are used [28, 29]. Another reason for heterogeneity in online information
17 may therefore be due to the fact that sites are written by different groups and institutions with variable
18 approaches to management who place emphasis on areas important to their practice.

19 This study has a number of limitations. Only 20 websites, obtained from 49 search engine results, were
20 reviewed therefore the sample size was small. However, the authors believe that the sites reviewed are likely to
21 include most of the websites that patients and their families may visit because most people seeking information
22 on the internet rarely seek information beyond the first few pages of results [12]. Similarly, only a single search
23 term ‘venous malformation sclerotherapy’ was used in one search engine. Google was chosen as the single
24 search engine to use as it is globally the most common search engine used [11]. However, a check for similarity
25 with the search engines Yahoo! and Bing was made. The use of various search term combinations across
26 multiple search engines may have yielded different results. This limitation is also a problem for information
27 seekers and is compounded when seeking information regarding Sclerotherapy for venous malformations. Due
28 to inconsistent nomenclature, even experts may find it difficult to find information from the scientific literature.
29 For example, hemangioma continues to be commonly misused to describe any type of vascular anomaly and the
30 term cavernous hemangioma is incorrectly used interchangeably for either a deep/subcutaneous infantile
31 hemangioma or venous malformation [30, 31]. Broadening the search terms may have resulted in more non-
32 relevant sites which would have been excluded, for example using the search term ‘venous sclerotherapy’
33 returns numerous sites concerned with treatment of varicose veins.

34 A further limitation lies in the application of the tools used. The Flesch Reading Ease Score, although well used,
35 bases scores solely on sentence length and word complexity, without accounting for other factors that might aid
36 comprehensibility (such as diagrams, pictures and layout). As such, the Flesch Reading Ease Score might not
37 directly correlate with a patient’s understanding of information. Finally, the methods used to assess the sites did

1 have some degree of subjectivity; this was minimized by using two reviewers and reaching consensus where
2 there was disagreement.

3 Many previous studies assessing online patient information, including studies regarding radiological procedures,
4 have used the LIDA tool [26, 32–35]. This is a validated instrument that assesses websites with respect to three
5 domains of quality: validity, reliability and accessibility of information. This is done using a combination of an
6 online tool and a form completed by an assessor [36]. Assessment of this tool may have allowed a comparison
7 of information regarding sclerotherapy for venous malformations with other radiological procedures, however
8 the LIDA tool is no longer easily and freely accessible online and therefore we did not include this in our
9 methods.

10 Sclerotherapy for venous malformations is generally performed at tertiary referral centers. Most primary and
11 secondary care physicians are likely to care for patients undergoing this treatment very rarely. Therefore, the
12 sites analyzed may be a source of information for clinicians too. The requirements for this group of information
13 seekers are different from that of patients. For example, non-compliance with American Medical Association
14 and National Institute of Health guidelines regarding readability may be ignored for these users.

15 A potential solution to the problems identified may be for expert groups providing sclerotherapy to create a
16 unified website in accordance with the quality and readability benchmarks referenced above, with a stratified
17 information portfolio to cater to different consumer needs. In the meantime, clinicians should account for the
18 disparity in quality and readability of patient information sites during face to face consults and wherever
19 possible patients and their families should be guided to sites with comprehensible information.

20 **Conclusion**

21 Online information regarding sclerotherapy for venous malformations is heterogeneous in quality and may be
22 too difficult for patients and their families to understand. Radiologists should be aware of potential disparity in
23 information about venous malformations accessed by their patients and their families, and should advise them
24 accordingly.

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2 None

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4 **Conflicts of interest**

5 We certify that there is no actual or potential conflict of interest in relation to this article.

1 **Figure Legends**

2 **Fig. 1**

3 Percentage of sites including clinical information points on the information checklist.

4

5

1 **Table Legends**

2 **Table 1**

3 Evaluation of assessment tools used (Flesch Reading Ease Score [13], Journal of the American Medical
4 Association benchmarks [16] and HONcode [17])

5

6 **Table 2**

7 Authors' checklist used to assess breadth of information on each website.

8

9

10

1 Tables

2 Table 1

3 Evaluation of assessment tools used (Flesch Reading Ease Score [13], Journal of American medical association benchmarks [16] and HONcode [17])

Test	What is assessed	Score	Advantages	Disadvantages
FRES (Flesch Reading Ease Score) [13]	Readability using the formula: $206.835 - 1.015 \left(\frac{\text{total words}}{\text{total sentences}} \right) - 84.6 \left(\frac{\text{total syllables}}{\text{total words}} \right)$	0 (hardest) – 100 (easiest)	<ul style="list-style-type: none"> • Freely accessible • Automated – prevents subjectivity 	<ul style="list-style-type: none"> • As text is copied into assessment tool, irrelevant information may not be removed prior to assessment e.g. hyperlinks to other webpages
JAMA Benchmarks [16]	Quality of healthcare electronic content. <ul style="list-style-type: none"> • Authorship • Attribution • Disclosure • Currency 	1 – 4 (each standard either met or not)	<ul style="list-style-type: none"> • Free 	<ul style="list-style-type: none"> • Subjective
HONcode certification [17]		HONcode logo Present	<ul style="list-style-type: none"> • Easy to assess • Certification signifies 	<ul style="list-style-type: none"> • Lack of certification does not always signify lack of quality

		or Absent	website has been independently evaluated to have met ethical standards	<ul style="list-style-type: none"> HONcode certification requires fee paid by website
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1

2

3 **Table 2**

4 Authors' checklist used to assess breadth of information on each website.

Item no. Item

Technique:

- 1 Indicates sclerotherapy is carried out by interventional radiologists
- 2 Indicates several sclerotherapy sessions may be required before improvement is observed
- 3 Discusses how sclerotherapy works
- Discusses possible sclerosing agents which may be used:
- 4 Sodium tetradecyl sulfate/Fibrovein/Sotradecol/Thromboject
- 5 Bleomycin
- 6 Ethanol

Outcome/Post procedure course:

- 7 Indicates that the venous malformation may initially look worse
- 8 Indicates that the treated site may be painful/bruised following the procedure

Risks mentioned:

- 9 Skin damage
- 10 Nerve damage
- 11 Infection
- 12 Haemoglobinuria/renal impairment
- 13 Lung fibrosis (if bleomycin is mentioned as an agent)

Alternative/adjunctive treatments discussed:

- 14 Compression garments
 - 15 Surgery
- Adjunctive interventional radiology therapies:
- 16 Coil embolization
 - 17 Glue embolization
 - 18 Endovenous laser ablation

Images:

- 19 Site has image(s) of a venous malformation
- 20 Site has image(s) of a venous malformation pre and post treatment
- 21 Site has image(s) of complications of sclerotherapy e.g. skin blisters