Information for oral and maxillofacial patients: can it be improved?

H. Parvez [a], M.S. Noorani [b], N. Pandis [c], M.T. Cobourne [a], J. Seehra [a,*]

[a] *Department of Orthodontics, Faculty of Dentistry, Oral and Craniofacial Sciences, King's College London, Floor 22, Guy's Hospital, Guy's and St Thomas NHS Foundation Trust, London, SE1 9RT, United Kingdom*

[b] *Department of Orthodontics, Institute of Dentistry, Barts and The London School of Medicine and Dentistry, Queen Mary University of London, London, United Kingdom*

[c] *Department of Orthodontics and Dentofacial Orthopedics, Dental School/Medical Faculty, University of Bern, Freiburgstrasse7 CH-3010, Bern, Switzerland*

Abstract

The aim and objective of this study was to evaluate the quality and readability of leaflet and online Oral and Maxillofacial Surgery patient information leaflets (PILs). The quality, readability and grade level of each PIL was assessed using the DISCERN, Flesch Reading Ease and Flesh-Kincaid Grade Level instruments respectively. In total, 140 patient information leaflets were assessed. For both leaflet and online PILs, many items of the DISCERN instrument were deemed of low quality and poorly reported. The median overall quality score was 30.2. Variation in the quality and readability scores between leaflet and online PILs and those produced by various societies was evident. Overall, PILs were deemed to be of moderate quality. Online PILs were of lower quality, more difficult to read and aimed at a higher reading age level.
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Introduction

Patients should now be informed of potential risks of treatment as part of the treatment consent process.[1] Patient information Leaflets (PILs) can contribute towards the informed consent process and have reported to assist decision-making.[2] Additional reported benefits of PILs include: providing awareness and information to change behaviors, educating patients,[3] increasing patient's overall satisfaction with clinicians,[4] reducing anxiety and offering reassurance[5] and improving patient satisfaction.[6] PILs are popular, with the majority of patients preferring written information and leaflets.[7] PILs can be of variable quality due to poor content, structure and writing style.[8,9] Ideally, the content used in the PILs should easily be understood by patients, easily read and remembered to enhance the communication between the doctor and the patient.[4]

Considering the reported benefits of PILs it is important that clinicians are confident regarding the content and quality of PILs they provide their patients.[9] The DISCERN tool is an instrument designed to assist professionals and patients with evaluating the quality of written healthcare information and hence allowing patients to make more well-informed decisions.[10] The Flesch Reading Ease and Flesch-Kincaid Grade Level scales have been used to assess the readability of the patient information leaflets.[11,12] Previous assessment of both leaflet PILs[13,14,15] and information provided online[16,17,19] using the DISCERN instrument has reported

* Corresponding author at: Department of Orthodontics, Faculty of Dentistry, Oral and Craniofacial Sciences, King's College London, Floor 22, Guy's Hospital, Guy's and St Thomas NHS Foundation Trust, London, SE1 9RT, United Kingdom.

E-mail address: jadbinderpal.seehra@kcl.ac.uk (J. Seehra).

the quality of information to be sub-optimal. In addition, the readability of orthodontic patient information leaflets have been shown to aimed at a higher reading age than the recommended population standard hence potentially reducing their effectiveness.[14,19] Online PILs also tend to be written for individuals with a high reading level.[16,20] The aim and objective of this study was to evaluate the quality and readability of patient information leaflets (PILs) produced by national oral and maxillofacial societies.

Material and methods

An electronic search was conducted to identify PILs produced by National Oral and Maxillofacial societies. The following keywords "maxillofacial surgery" and "patient information leaflets" were entered into Google (www.google.com), google scholar search engines and PubMed. Only English language PILs were included. All potential PILs (online and pdf versions) were initially screened by one author (HP). These were then independently assessed by two investigators (HP and JS). All disagreements were resolved by discussion.

The DISCERN tool consists of 16 items that are categorised into three sections: authenticity (questions 1-8), information pertaining to treatment options available to patients (questions 9-15), and an overall rating of the quality of the source of information (question 16). Each item was scaled on a five-point system, where a score of 1 was used for sources that were seriously flawed and a score of 5 for high quality sources that had minor flaws. Each question on the DISCERN tool was independently graded by two authors (HP and MSN), together producing a score for each PIL. For domains 1-15 of the DISCERN instrument, each was scored on a scale between 1(lowest)- 5(highest). The total sum of all domains for each PIL was obtained, which produced overall scores ranging from 15 (minimum) to 75 (maximum).[15] Two investigators (HP and MSN) were calibrated by assessing the quality of 5 PILs with direct referral to the DISCERN instrument and associated explanation per item. The quality of each PIL was assessed independently.

One author (HP) was responsible for assessing the readability of the PILs. The entire text of each PIL was copied into Microsoft Word and a corresponding Word file was created. The Word files were then compared against their corresponding pdf versions in order to ensure accuracy of the text. The text was then uploaded into an online tool located at www.readability-score.com. Two assessment tools (Flesch Reading Ease (FRE)[21] and Flesh-Kincaid Grade Level)[22] were used to assess readability and grade level. The Flesh readability tools considers the length of sentences and the number of syllables in each word along with different weighting factors for each variable to calculate the reading ease and grade level respectively. The scoring system for the assessment of readability was based on the methodology employed by previous studies.[12,13] The Flesh Reading Ease score ranges from 0 to 100, where 0 represents a passage that is very difficult to read and 100 a very simple one.[13] The overall read-

Table 1
Inter-assessor reliability scores per DISCERN instrument item.

DISCERN item	Level of agreement (%)
1. Are the aims clear?	45
2. Does the leaflet achieve its aims?	39
3. Is it relevant?	40
4. Is it clear what sources of information were used to compile the publication (other than the author or producer)?	76
5. Is it clear when the information used or reported in the publication was produced?	81
6. Is it balanced and unbiased?	41
7. Does it provide details of additional sources of support and information?	76
8. Does it refer to areas of uncertainty?	57
9. Does it describe how each treatment works?	35
10. Does it describe the benefits of each treatment?	42
11. Does it describe the risks of each treatment?	56
12. Does it describe what would happen if no treatment is used?	39
13. Does it describe how the treatment choices would affect overall quality of life?	51
14. Is it clear that there may be more than one possible treatment choice?	36
15. Does it provide support for shared decision making?	62
16. Overall quality	53

ability of a PIL based on the FRE score was classified into different categories depending on its score. A score below 50 was classified as difficult; a score above 60 was classified as fairly difficult and a score above 80 was classified as comfortable reading text.[12]

Statistical analysis

All data was entered into an Microsoft excel data capture sheet. Inter-assessor reliability was assessed using the Kappa statistic (Table 1). Descriptive statistics for individual reporting items of the DISCERN instrument were calculated and converted to a percentage scale. A non-normal distribution of the data was assessed and confirmed from graphical methods. Quantile regression was used in order to identify predictors associated with the score. Standards errors and consequently 95% confidence intervals were calculated using non-parametric bootsrapping with replacement with 10,000 iterations. A two-tailed p value of 0.05 was considered statistically significant. Statistical analyses were performed using STATA software version 14.2 (Stata Corporation, College Station, Texas, USA).

Results

A total of 140 PILs ((leaflet (N = 62) and online (N = 78)) were included in this study. The inter- assessor level of agreement (%) for each item of the DISCERN instrument ranged between 35% (lowest)-81% (highest). For leaflet and online PILs, the largest number were produced by British

Table 2
Source and numbers of PILs included (N = 140).

Source	No. (%) (n = 140)
Leaflet (n = 62)	
Oral and Maxillofacial Surgeons (OMS)	11(8)
Australian and New Zealand Association of Oral and Maxillofacial Surgeons (ANZAOMS)	3 (2)
The South African Society of Maxillofacial and Oral Surgeons (SASMFOS)	10 (4)
British Association of Oral and Maxillofacial Surgeons (BAOMS)	38 (27)
Online (n = 78)	
Canadian Association of Oral and Maxillofacial Surgeons (CAOMS)	10 (7)
Association of Oral and Maxillofacial Surgeons in Singapore (AOMS)	3 (2)
Australian and New Zealand Association of Oral and Maxillofacial Surgeons (ANZAOMS)	11 (10)
Association of Oral and Maxillofacial Surgeons of India (AOMSI)	8 (6)
Pakistan Association of Oral and Maxillofacial Surgeons (PAOMS)	10 (7)
Ontario Society of Oral and Maxillofacial Surgeons (OSOMS)	8 (6)
Pennsylvania Society of Oral and Maxillofacial Surgeons (PSOMS)	14 (10)
New Jersey Society of Oral and Maxillofacial Surgeons (NJSOMS)	9 (6)
American Society of Oral and Maxillofacial Surgeons (ASOMS)	5 (4)

Table 3
The ratings of individual DISCERN item (leaflets) (n = 62).

DISCERN item	Rating		
	1 and 2 (low quality)	3 (moderate quality)	4 and 5 (high quality)
1. Are the aims clear?	19	3	40
2. Does the leaflet achieve its aims?	4	8	50
3. Is it relevant?	6	18	38
4. Is it clear what sources of information were used to compile the publication (other than the author or producer)?	53	8	1
5. Is it clear when the information used or reported in the publication was produced?	49	2	11
6. Is it balanced and unbiased?	32	17	13
7. Does it provide details of additional sources of support and information?	52	10	0
8. Does it refer to areas of uncertainty?	59	1	2
9. Does it describe how each treatment works?	14	21	27
10. Does it describe the benefits of each treatment?	43	15	4
11. Does it describe the risks of each treatment?	27	8	27
12. Does it describe what would happen if no treatment is used?	29	21	12
13. Does it describe how the treatment choices would affect overall quality of life?	38	20	4
14. Is it clear that there may be more than one possible treatment choice?	53	5	4
15. Does it provide support for shared decision making?	60	1	1
16. Overall quality	10	33	19

Association of Oral and Maxillofacial Surgeons (27%) and Pennsylvania Society of Oral and Maxillofacial Surgeons (10.0%) respectively (Table 2). The ratings of individual DISCERN item (Leaflets) is shown in Table 3. Overall, these were deemed of moderate quality (Item 16). The ratings of individual DISCERN items (Online) (N = 78) are shown in Table 4. Similar to leaflet types, online PILs were deemed of moderate quality.

The overall DISCERN quality score was 30.2 (N = 140). The median Discern quality scores for Leaflet and online PILs (N = 78) is shown in Table 5. There was a significant difference in the quality scores between Leaflet and Online PILs (−4.86, 95 % CI: −6.26, −3.47, p = 0.001).

Table 6 reports the median readability scores for both Leaflet and Online PILs. Differences in the median readability scores are shown in Table 7.

Discussion

It is essential that clinicians and healthcare providers are confident about the quality of patient information leaflets they utilise in their clinical practice.[9] The DISCERN instrument has been developed as "gold standard" reference for developers of patient information leaflets (PILs).[10] It has previously been used in multiple medical and dental specialties to assess

Table 4
The ratings of individual DISCERN items (Online) (N = 78).

DISCERN item	Rating		
	1 and 2 (low quality)	3 (moderate quality)	4 and 5 (high quality)
1. Are the aims clear?	62	10	6
2. Does the leaflet achieve its aims?	16	38	24
3. Is it relevant?	12	38	28
4. Is it clear what sources of information were used to compile the publication (other than the author or producer)?	78	0	0
5. Is it clear when the information used or reported in the publication was produced?	60	0	18
6. Is it balanced and unbiased?	33	38	7
7. Does it provide details of additional sources of support and information?	74	4	0
8. Does it refer to areas of uncertainty?	73	5	0
9. Does it describe how each treatment works?	29	24	25
10. Does it describe the benefits of each treatment?	71	3	4
11. Does it describe the risks of each treatment?	70	5	3
12. Does it describe what would happen if no treatment is used?	28	34	16
13. Does it describe how the treatment choices would affect overall quality of life?	62	12	4
14. Is it clear that there may be more than one possible treatment choice?	62	9	7
15. Does it provide support for shared decision making?	73	5	0
16. Overall quality	25	49	4

Table 5
Median DISCERN quality scores for Leaflet and Online PILs per source.

Source	Median (IQR) DISCERN quality score
Leaflet (n = 62):	
Oral and Maxillofacial Surgeons (n = 11)	34.5 (31–36.5)
Australian and New Zealand Association of Oral and Maxillofacial Surgeons (n = 3)	31.5 (30.5–34)
The South African Society of Maxillo Facial and Oral Surgeons (n = 10)	34 (32–43.5)
British Association of Oral and Maxillofacial Surgeons (n = 38)	30.75 (29.5–35)
Online (n = 78):	
Canadian Association of Oral and Maxillofacial Surgeons (n = 10)	27.5 (25–28.5)
Association of Oral And Maxillofacial Surgeons in Singapore (n = 3)	31.5 (27.5–38.5)
Australian and New Zealand Association of Oral and Maxillofacial Surgeons (n = 11)	31 (29–33.5)
Association of Oral and Maxillofacial Surgeons of India (n = 8)	27.75 (25.5–29.5)
Pakistan Association of Oral and Maxillofacial Surgeons (n = 10)	23.75 (20–25.5)
Ontario Society of Oral and Maxillofacial Surgeons (n = 8)	27.25 (27.75–28.25)
Pennsylvania Society of Oral and Maxillofacial Surgeons (n = 14)	30 (28–31.5)
New Jersey Society of Oral and Maxillofacial Surgeons (n = 9)	29 (27.5–31)
American Society of Oral and Maxillofacial Surgeons (n = 5)	25.5 (24–27.5)

the quality of PILs. Previous investigations have reported variation in the quality of PILs when assessed in relation to the DISCERN instrument.[13–15,21]

Regarding leaflets deficient reporting of specific items of the DISCERN instrument were identified (Tables 3 and 4). Similar findings have been reported. Lewis and Newton[15] reported deficiencies in aims, reference to sources of information or date of production, risks of treatment, effect of choosing not to have treatment, effect of treatment on overall quality of life, and support for shared decision making. Seehra et al.[14] reported deficiencies in description of aims (47.2 %), description of sources (100 %), details of additional sources (69.4 %), consequences of no treatment (50 %), possible treatment options (38.8 %) and support for a shared decision process (61.1 %).

Based on item 16 (overall quality rating) of the DISCERN instrument, both the Leaflet and Online PILs included in this study were deemed to be of moderate quality. The overall quality score for the total sample was 30.2. PILs that were available online were of lower quality compared to leaflet PILs. This appears to be consistent with previous literature. Using the DISCERN instrument the mean quality score of online health information for pediatric neuro-oncology specialities was 34.5 with the majority categorized as poor quality.[18] The mean quality score for both orthodontic and medical PILs has been reported at 44 and 35.2 respectively indicating a slighter higher quality compared to online sources.[14,15]

The readability content of patient information materials should not be beyond the reading age of a 12-year-old and

Table 6
Median readability scores for Leaflet and Online PILs per source.

Source	Median (IQR)
Leaflet:	
Oral and Maxillofacial Surgeons (n = 11):	
Flesch Reading Ease	49.7 (42– 53.4)
Flesch-Kincaid grade level	10.8 (10.1– 11.9)
Australian and New Zealand Association of Oral and Maxillofacial Surgeons (n = 3)	
Flesch Reading Ease	50 (47.9–52.4)
Flesch-Kincaid grade level	10.3 (9.5–10.3)
The South African Society of Maxillofacial and Oral Surgeons (n = 10)	
Flesch Reading Ease	50.5 (42.5–59.6)
Flesch-Kincaid grade level	10.9 (9–12)
British Association of Oral and Maxillofacial Surgeons (n = 38)	
Flesch Reading Ease	64.8 (62–68.5)
Flesch-Kincaid grade level	8 (7.4–8.6)
Online:	
Canadian Association of Oral and Maxillofacial Surgeons (n = 10)	
Flesch Reading Ease	36.6 (24.7–48)
Flesch-Kincaid grade level	12 (11.2–12)
Association of Oral And Maxillofacial Surgeons in Singapore (n = 3)	
Flesch Reading Ease	55.8 (52.7–68.8)
Flesch-Kincaid grade level	9 (6.6–9.5)
Australian and New Zealand Association of Oral and Maxillofacial Surgeons (n = 11)	
Flesch Reading Ease	34.4 (31–43.1)
Flesch-Kincaid grade level	12 (12–12)
Association of Oral and Maxillofacial Surgeons of India (n = 8)	
Flesch Reading Ease	49.9 (36.2–62.4)
Flesch-Kincaid grade level	10.7 (8.9–11.7)
Pakistan Association of Oral and Maxillofacial Surgeons (n = 10)	
Flesch Reading Ease	38.5 (29–45.2)
Flesch-Kincaid grade level	12 (12–12)
Ontario Society of Oral and Maxillofacial Surgeons (n = 8)	
Flesch Reading Ease	48.7 (40.1–65.6)
Flesch-Kincaid grade level	10.4 (7.85–12)
Pennsylvania Society of Oral and Maxillofacial Surgeons (n = 14)	
Flesch Reading Ease	50.8 (47.2–56.6)
Flesch-Kincaid grade level	10.2 (9.3–11.2)
New Jersey Society of Oral and Maxillofacial Surgeons (n = 9)	
Flesch Reading Ease	52 (46.5–52.9)
Flesch-Kincaid grade level	10.4 (9.7–11.4)
American Society of Oral and Maxillofacial Surgeons (n = 5)	
Flesch Reading Ease	41.9 (40.2–56.1)
Flesch-Kincaid grade level	11.8 (10–12)

Table 7
Medians, median differences (observed coefficients) and 95% confidence intervals (CI) for the differences in readability scores for both leaflet and online types.

Predicator variables	No.	Median	Observed coefficient	95% CI	p value
Flesch Reading Ease score:					
Leaflet	62	61.5	−14.6	−20.0 to 9.16	<0.001
Online	78	46.6			
Flesch-Kincaid grade level:					
Leaflet	62	8.6	2.80	1.83 to 3.78	<0.001
Online	78	11.4			

for the population in the United Kingdom and United States not surpass a reading level of 10-11 years old (Grade 5-6) and 13-14 year old (8th grade) respectively.[9,23,24] The use of online resources to search for health-related information is increasing but the quality and readability of the information is debatable.[25] In this study, the median FRE for Leaflet PILs and Online PILs was 61.5 and 46.6 and the Flesch–Kincaid Grade Level scores for leaflet PILs was online PILs and 8.6 and 11.4 respectively. Dental practice leaflets have found leaflets to be 'difficult to read' with a mean FRE level ranging between 55.2 (SD 12.5) and 72.19 (SD 4.75).[13] Similarly, hospital patient information leaflets have been assessed to have a mean Flesch-Kincaid reading grade of 7.8 which exceeds the comprehension of readers.[23] There was

also a difference between the readability of leaflet PILs and online PILs as well as those produced by different societies. In comparison to the leaflet PILs, online PILs achieved a lower FRE scores and higher Flesch-Kincaid Grade Level scores. Leaflets produced by Australian and New Zealand Association of Oral and Maxillofacial Surgeons had the lowest FRE score and Flesch-Kincaid Grade Level score. In contrast, British Association of Oral and Maxillofacial Surgeons achieved the highest FRE score of 64.8 and Flesch-Kincaid Grade Level score of 8.

Readability tools are measurement criteria based on the length of sentences, number of syllables, or vocabulary indexes. A shortcoming of this is that a word may score well using a given measure of readability, even though it may not be a commonly used term. The replacement of healthcare terminology with layman's terms would not be fully achievable without potential loss of accuracy, hence a certain degree must be included at the expense of higher readability scores.

Variability in the level of agreement/item of DISCERN between the two assessors was evident. This ranged from 35% (item 9) to 81% (item 5), which could limit the generalisability of the findings (Table 1). This could be attributed to the difference in experience between the two assessors and potential rater bias. The decision to include leaflets from national societies was based on the accessibility and availability but may result in a degree of selection bias. In addition, as the investigators were not blinded, a further degree of bias may have been introduced.

Leaflets produced by for-profit companies such as Krames were not evaluated despite their products being widely used. An assessment of the level of expertise and financial support used in their development was beyond the scope of this study and is not a variable assessed by DISCERN. This could be a shortcoming, as the quality of leaflets could perhaps be influenced by the level of support and expertise used. Potentially relevant non-English leaflets may have also been excluded. The decision to include those in English alone was to reduce interpretation errors when assessed with DISCERN.

The aim of this study was to provide baseline data, highlight the overall deficiencies and quality of a large number and broad spectrum of oral and maxillofacial PILs. The individual treatment intervention of each PIL was not assessed or compared but could be explored in future studies.[15,16,25] Despite patient information being reported to improve patient satisfaction,[6] the relationship between the quality of information leaflets and patient satisfaction needs further investigating to verify if PILs can have a positive influence on treatment outcomes. Ideally, Patient information leaflets should be easily accessible, understood by a wide-ranging readership, based on current evidence and designed at the appropriate reading age.[9,10] The quality of future PILs can be further enhanced if the domains of the DISCERN instrument are followed in the design stage.

Within the study limitations the quality of Oral and Maxillofacial Surgery PILs have been deemed of moderate quality. Informed consent is required when undertaking surgical procedures and PILs have been shown to contribute to this process.[1,2] However, they should be only used as an aid in the informed consent process and not replace a verbal discussion between clinicians and patients as there is a risk that poor quality leaflets may represent a breach in the duty of care, if clinicians are not aware of the shortcomings of leaflets in terms of both content and readability. From a medico-legal aspect, if patient information leaflets have been used during the treatment consent process, it would be prudent for the clinician to document in the clinical notes that the patient has read and understood this additional information.

The results of this study have confirmed that clinicians cannot solely rely on PILs during the consenting of oral and maxillofacial procedures. When explaining healthcare options to patients, clinicians may wish to consider providing supplemental information (leaflet and online) including information describing possible treatment options, support for a shared decision making, describing risks of each treatment and a description of how different choices affect overall quality of life.

Conflict of interest

We have no conflicts of interest.

Ethics statement/confirmation of patients' permission

Both ethical approval and patient consent was not required.

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