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Introduction

Traumatic brain injury (TBI) is a global public health problem, and amongst the leading causes of mortality and morbidity worldwide [1]. Although recent medical advances have improved survival following TBI, many survivors continue to experience troublesome neurocognitive symptoms several years following the initial injury [2]. Whilst more severe injuries are associated with life-long impairments in functional status, even milder injuries result in significant neuro-cognitive and affective symptoms [3]. Therefore, there is increasing recognition of TBI as a chronic disease rather than an isolated acute insult. In addition to impacting patient quality of life, there is considerable burden to families and/ or caregivers as deficits can be complex and hinder activities of daily living [4, 5]. Given the chronic nature of the disease, the provision of accessible and high-quality information is vital to help sufferers cope with their condition and for carers to anticipate their needs. Despite evidence from over two decades ago that highlighted insufficient information provision for families as an issue post-TBI [6, 7], improving patient education remains a relatively inactive area of research [8]. In recent years, the Internet has become a pertinent source of information for patients due largely to its inherent accessibility [9]. Studies across several countries demonstrate that as many as 80% of Internet users habitually seek health information online [10]. However, increasing reliance on the Internet for health information has shown mixed consequences for the general public [11, 12]. This is due to readily available information that may or may not be applicable to the patient's individual situation. This can result in unnecessary anxiety, misinformation, inappropriate self-diagnosis, and mistrust of qualified healthcare professionals. This is more relevant than ever during this pandemic taken the delays and cancellations in clinic appointments. Also, recent studies demonstrate that online information-seeking behaviour is prevalent across both younger [13] and older age groups [14]. Therefore, there is a dire need for rigorous evaluation of available online information to: (i) identify high quality information that can be recommended for patient use; (ii) highlight gaps in available information to inform the development of better resources; and (iii) harness the potential of optimal online resources for maximising benefit to patients with TBI and their caregivers. In this study, we evaluate the accessibility, relevance, and readability of information regarding TBI from major online search engines.

Methods

The patient online user experience was simulated by entering specific search terms into two major online search engines (Google™, Yahoo™) on 17th February 2021. Search terms included: “head injury”, “Traumatic Brain Injury”, “TBI”, “TBI death”, “TBI surgery”, “Traumatic Brain Injury surgery outcome”, and “TBI outcome”. The first 30 hits per search were screened for relevancy, context, and duplication between search engines (see **Figure 1**). Two authors (RB and JB) reviewed eligible websites using the following tools: DISCERN tool [15], JAMA Benchmark [16], Flesch-Kincaid Grade Level (FKGL), and Flesch Reading Ease Score (FRES) [17].

The DISCERN tool [15] is a scoring system that assesses the quality of online information sources with a 16 question 5-point-Likert scale index. It examines a range of properties including reliability, relevancy, and the quality of patient information available. It is widely recognised as a good measure of the quality of information provided in both a healthcare professional and patient-centric manner. The JAMA benchmark criteria [16] is a 5-point scale that examines four domains (authorship, attribution, disclosure and currency) of an online information source. It is a streamlined measure of credibility, often used as an adjunct with other quality assessment tools. FKGL and FRES are tools that assess the readability of written sources to a reader. It uses variables such as total length, words, syllables, and sentences in a source and functions with the use of pre-determined constants to provide a value. The FKGL of an online source provides the required educational level for the reader to understand the source. Similarly, FRES uses a 0 to 100 scale where a higher rating indicates greater readability of the source.

Quality assessment was performed using the DISCERN and JAMA Benchmark tools. Readability assessment was performed using FKGL and FRES scores. The association between ranking of websites on Google™ search and quality (DISCERN scores) was examined to identify the risks associated with lower quality websites appearing in higher ranks. The association between quality (DISCERN scores) and readability (FKGL and FRES scores) was also examined to identify whether higher quality articles necessitated higher

levels of education in order to be understood. Scatter plots and lines of best fit (linear least squares regression) were generated for visual identification of potential relationships between the relevant variables. The co-efficient of determination (R^2) was calculated as an approximate indicator of potential associations. Graphs and analyses were generated using Microsoft Excel (Mac, Version 16.43) and GraphPad Prism software (GraphPad Software Inc., San Diego, CA, USA).

Results

A total of 202 websites were eligible for assessment (see **Figure 1**). Responsible organisations for included websites included: academic (77/202, 38.1%), not-for-profit (75/202, 37.1%), governmental (26/202, 12.9%), commercial (14/202, 6.93%), and media (8/202, 3.96%) sources. The remainder were uncategorised (3/202, 1.49%).

Quality

Quality of included websites were assessed using the DISCERN score and JAMA Benchmark Score (**Table 1**). Information regarding the symptoms, management, diagnosis, and prognosis of TBI was evaluated. Websites were categorised as very poor (35/202, 17.3%), poor (84/202, 42.6%), fair (69/202, 34.2%), good (10/202, 5.0%), or excellent (4/202, 2.0%) (**Figure 2-A**). Mean DISCERN score was 36.5/80 (SD 9.9; 19-66), signifying an overall poor global quality. Mean JAMA Benchmark score was 2.8 (SD 1.1; range), with the majority of included websites scoring 3 (63/202, 31.2%) or 4 (71/202, 35.1%) (**Figure 2-B**).

Readability

Readability was evaluated with the FKGL and FRES scores (**Table 1**). The majority of websites required 9 – 12 years of education (113/202; 55.9%) according to FKGL scores and were categorised as 'Difficult' on FRES scores (94/202; 46.5%) (**Figure 3**).

Associations

Given the greater likelihood of choosing websites that rank higher on an online search, we assessed the relationship between quality of included websites (DISCERN score) and ranking on the Google™ search (**Figure 4**). Search terms demonstrating potential associations

between ranking and DISCERN scores included: “TBI surgery outcome” ($R^2 = 0.42$), “Head injury” ($R^2 = 0.38$), and “TBI surgery” ($R^2 = 0.35$). Next, we examined the relationship between quality (DISCERN score) and readability (FKGL and FRES scores) across all included websites (**Figure 5**). No clear association was identified with FKGL ($R^2 = 0.0040$) or FRES ($R^2 = 0.0099$) scores. Finally, we examined differences in DISCERN scores based on the website source (**Figure 6**). Whilst the median DISCERN score was in the ‘Poor’ category for all sources, academic sources ranked highest (Median 37; IQR 9) and media sources were ranked lowest (Median 31; IQR 6).

Discussion

Patient education is accepted as a key step to facilitating active participation in healthcare decisions [18]. Increasing online-information seeking by patients means that healthcare professionals must be equipped to provide informed guidance on suitable websites. This is essential to avoid the deleterious consequences of patient misinformation. Achieving adequate quality online resources will help patients and caregivers to develop a clearer understanding of their current situation. This will help cope with the emotional and practical implications of managing TBI from a lifestyle perspective. Importantly, it also supplements the physician-patient relationship by ensuring a good level of background understanding prior to consultations, which may subsequently: (i) enhance patient/ caregiver understanding of healthcare information provided by physicians; and (ii) promote the opportunity for more personalised discussion regarding individual circumstances. To date, only two studies have explored the quality of online resources for TBI patients and their caregivers [19, 20]. Specifically, the quality and readability of online information regarding TBI-associated cognitive deficits was assessed in one study [19]. Less than one third of included websites were below the recommended reading age, and there was significant variability in the quality of information. Similarly, another study of readability of online resources for post-traumatic epilepsy revealed that only 6.2% of websites were at the recommended sixth grade level of readability [20]. In our study, we evaluated the quality, readability, and accessibility of online information regarding various aspects of TBI. Whilst a few ‘Excellent’ quality websites exist (see **Table 2**), the majority of websites scored ‘Poor’ or ‘Very Poor’. Analysis of the top ten search results demonstrated no correlation between ranking and DISCERN score, indicating a disparity between quality and accessibility. In

addition, evaluation of the relationship between quality and readability revealed no clear association. Given evidence that patients of lower socioeconomic status are at a higher risk of poorer outcomes [21], it is important that quality and readability are achieved in tandem. Therefore, there is an unmet demand for effective online resources for patients with TBI and caregivers, with: (i) accurate content; (ii) ease of readability; and (iii) better accessibility. This may be due to a lack of wider appreciation of TBI as a chronic disease, and the importance of effective patient education.

The use of online or multimedia resources for patient education has been demonstrated across several disease contexts including cardiovascular disease [22], diabetes [23], rheumatoid arthritis [24], cancer care [25], and palliative care [26]. Given that patients are estimated to only recall a small proportion of the information provided during healthcare consultations [27], the Internet provides an excellent opportunity to rectify this. Examples of successful online portals for patients with back pain [28] and children with congenital heart disease [29] exist, but no initiatives in the context of TBI are present to date. A recent systematic review and meta-narrative assessed the quality of online health information across different health conditions and organisations [30]. Interestingly, websites from government organisations displayed the highest DISCERN scores whilst media-related sources scored the lowest. This is partly in keeping with our results, which demonstrated that academic sources had the highest median DISCERN scores and media sources had the lowest. Whilst some variation was observed between different medical specialities and quality of online information, all of them scored within the 'Good' DISCERN category. On the other hand, greater variation was observed when the HON Code of Conduct scale was used. Therefore, the method of assessment must be taken into account when evaluating studies examining quality of online information. It was noted that included studies did not report 'Excellent' DISCERN scores across any of the evaluated conditions. In contrast, in our study, the four highest scoring websites were within the 'Excellent' category, indicating that high quality resources do exist for TBI.

Although the Internet offers immediately accessible information, readability is an important component of evaluating resources. Ascertaining the optimal reading level for medical information can be difficult, as average reading level can vary within and between countries.

However, a recent systematic review of the readability of online health information in the USA and Canada reported that required reading levels consistently exceed the average reading level of the population, which was estimated at sixth grade level [31]. This poses an obstacle in the context of TBI in particular, as cognitive deficits may further impair patient comprehensibility. Indeed, in our study, the three highest DISCERN scoring websites also demonstrated FRE scores consistent with requiring college-level education. Furthermore, the majority of included websites (90/202 websites; 44.6%) required 9 – 12 years of education based on FKGL scores (**Figure 3**). We also examined whether readability is compromised to produce higher quality resources, as this may pose an issue in the development of resources in the future. However, neither FKGL nor FRE scores demonstrated strong associations with DISCERN scores across included websites (**Figure 5**). Therefore, future initiatives to produce online education resources must address both quality and readability of content. Given that TBI is a rapidly advancing field, existing organisations must ensure that healthcare information is regularly updated and written at an appropriate reading level. Based on the National Assessment of Adult Literacy in the US, information should be presented at a reading age of 6th grade or below [32], though this will vary globally. Healthcare professionals must also acknowledge the difficulties that may arise with readability, and provide patients with individualised recommendations.

It is widely recognised that the ranking of a website within the output of online search engines plays a pivotal role in its likelihood of selection [33]. Therefore, we examined the quality of highly ranking websites. Depending on the search terms used, we found varying associations with DISCERN scores. Ideally, a negative association between DISCERN score and position on the online search would indicate a higher likelihood of accessing higher quality websites. However, this was only demonstrated with the “TBI Surgery” search term, whilst the remaining search terms demonstrated either no clear associations or positive associations. The complex algorithms employed by major online search engines do not necessarily prioritise quality of content, highlighting the importance of healthcare professional involvement in creating and recommending online resources. On the other hand, website ranking is no longer a solitary metric for popularity, as search engine optimisation is an evolving phenomenon [34]. Organisations developing TBI resources

should also address other factors to achieve popularity such as an appealing user interface and maximising clickthrough rates, which will indirectly influence ranking.

Our choice of metrics for assessing quality and readability was based on their existing successful use within the literature. The DISCERN score [15] was initially developed as a tool for use by healthcare professionals and consumers to evaluate the quality of information regarding treatment choices for medical conditions. Its popularity is demonstrated by its use in the majority of included studies in a recent systematic review of the quality of online information [30]. This is likely due to its feasibility of use with a series of sixteen questions with Likert responses. However, the final DISCERN score is still subject to user bias as it is not directly related to the score from each question, but rather a global assessment. The JAMA Benchmark provides a more streamlined method for assessing quality, but is a more crude indicator of information reliability [16]. It has been noted that it is often used as an adjunct to more elaborate scoring tools in previous studies [35], and not in isolation. FKGL and FRES scores were developed several decades ago, and are well-established as methods for assessing readability [17]. Ease of analysis with online tools or Microsoft Word have significantly increased feasibility of use. Indeed, FKGL and FRES were the most commonly used tools in a recent systematic review of readability of online health information [31]. Furthermore, their reflection of required level of education is useful for gauging applicability to the general public. Only two authors reviewed eligible websites in our study, which may not be an entirely representative assessment. Future studies on the quality of neurosurgical online information should endeavour to include a greater number of reviewers and public involvement.

In this study, we aimed to appraise existing websites providing health information regarding TBI. Given the heterogeneity and broad scope of TBI, we did not assess information regarding specific treatment approaches. Instead, we explored broad aspects that are likely to be of concern to patients or caregivers, including surgery, outcomes, and mortality. Further studies may be required to investigate specific treatment approaches, such as types of surgical intervention or neurorehabilitation, and different severities of TBI. Given the paucity of high-quality, readable, and easily accessible online resources, however, it may be more prudent to direct efforts towards initiatives to remedy this. This could address several

facets of TBI, including: (i) symptoms and outcomes based on severity of TBI; (ii) the role of different types of intervention, including neurorehabilitation, clinical psychology, and neurosurgical input; (iii) a platform for patients and caregivers to share their experiences with others; and (iv) explaining that our current understanding of TBI is a changing phenomenon and inviting the public to get involved in research efforts. Ultimately, these resources should be developed in a multidisciplinary fashion, with the input of patients, caregivers, rehabilitation professionals, clinical psychologists, physiotherapists, occupational therapists, and neurosurgeons. Aside from developing better online resources, offering recommendations on the best available websites should form a routine component of the physician-patient consultation.

Conclusions

There is currently a paucity of online resources for TBI patients that achieve adequate quality, readability, and accessibility. Given the chronic nature of TBI and burden to both patients and caregivers globally, there is an unmet need for effective online resources. This should be achieved through a concerted effort between patients, caregivers, and multidisciplinary healthcare professionals. Our study findings will help healthcare professionals involved in the management of TBI to: (i) better address the needs of patients by recommending the most useful online resources; (ii) counsel patients regarding the risks of relying on the Internet as a primary source of healthcare information.

Figure Legends

Figure 1. Flowchart depicting website inclusion process for online information regarding various aspects of TBI.

Figure 2. Bar charts demonstrate percentage of included studies within different categories in DISCERN score (A) and JAMA Benchmark score (B) assessments of quality.

Figure 3. Bar charts demonstrate percentage of included studies within different categories in Flesch-Kincaid Grade Level (FKGL) (A) and Flesch Reading Ease Score (FRES) (B) assessments of readability.

Figure 4. Scatterplots depicting the relationship between accessibility (position of website in top 10 results from Google™ search engine) and quality of content (DISCERN score) for each search term. Titles indicate the relevant search terms used.

Figure 5. Scatterplots depicting the relationship between quality of content (DISCERN score) and readability, based on Flesch-Kincaid Grade Level (A) and Flesch Reading Ease Score (B).

Figure 6. Boxplots depicting quality of content (DISCERN score) based on website source.

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