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Patient information on schizophrenia on the internet



AIMS AND METHODS

The internet is an important source of mental health information. Given variable literacy levels in the general public, patient information websites need to be easily readable to prevent misunderstanding and consequent misinformation about mental health problems being propagated. The aim was to ascertain the readability of websites containing patient information about schizophrenia. Twenty websites containing patient information about schizophrenia generated by Google® were

analysed for Flesch Reading Ease and Flesch-Kincaid Grade Level.

RESULTS

According to standardised Flesch Reading Ease classification, 40% of the selected sites were classified as very difficult, 55% as difficult and 5% as fairly difficult. None were considered easy to read. There was a negative correlation of -0.798 (P < 0.001) between Flesch Reading Ease and Flesch-Kincaid Grade Level, which demonstrates the reliability of these results.

CLINICAL IMPLICATIONS

Easily accessed schizophrenia information websites do not score highly for readability. Those that produce websites should bear readability in mind when writing them in order to construct more readable sites. Ideally, these should be accredited by recognised organisations that evaluate readability. Clinicians should assess website information for readability before recommending them to patients or carers.

The internet is used as a source of mental health information by over 10% of the general population and over 20% of those with a history of mental health problems (Powell, 2006). It is one of the top three most reliable sources of information about mental health issues for 24% of users (Powell, 2006). It has the advantages of accessibility and anonymity, and so it is not surprising that people with disorders carrying a stigma (such as mental health problems) are more likely to use the internet when looking for health-related information (Berger et al, 2005). Such people are also more likely to seek medical help having first identified their symptoms using internet sites (Berger et al, 2005).

Schizophrenia is a common mental health illness and a conceptually complex one. Along with drug dependence and alcoholism, it is one of the most stigmatised mental health disorders (Crisp et al, 2005). It is also poorly understood by the lay public: when asked what they thought 'schizophrenia' meant, 42% of Britons associated it with 'multiple personality' or 'split personality' (Luty et al, 2006). The internet may be a valuable source of information to patients and their carers, as well as the general public, and help them engage with health services.

It is estimated that 45% of the UK population have limited literacy skills, reading at a level below the one necessary to cope with life and work (Organisation for Economic Co-operation and Development, 2003). The PRODIGY study estimated that the average reading age of the UK population was between 9 and 11 years (Wilson et al, 1998), while people with schizophrenia have significantly poorer language comprehension than controls (Condray et al, 1992). Specifically, they have trouble understanding complex syntax (Morice & McNicol, 1985). When interviewed in a qualitative study on patient information materials, people with schizophrenia stated they found much of the available written information too difficult to understand (Kingdon et al, 2004).

For these reasons, it is important that information about schizophrenia available on the internet be easily readable. Readability is not a measure of accuracy; rather, it is a measure of the simplicity of syntax and syllabic structure of a piece of text, and does not take into account the complexity of the subject matter presented. Readability of health-related information in other disciplines has been assessed using the Flesch-Kincaid Grade Level and Flesch Reading Ease (Flesch, 1973) score (Box 1).

Box 1.

Flesch Reading Ease

The output of the Flesch Reading Ease formula is a number from 0 to 100, with a higher score indicating easier reading.

The formula is as follows:

 $206.835 - (1.015 \times ASL) - (84.6 \times ASW)$

where

ASL = average sentence length (the number of words divided by the number of sentences)

ASW = average number of syllables per word (the number of syllables divided by the number of words)

Flesch-Kincaid Grade Level

The Flesch-Kincaid Grade Level formula produces an output of the US school grade of literacy required to read the text.

The formula is as follows:

 $(0.39 \times ASL) + (11.8 \times ASW) - 15.59$

where:

ASL = average sentence length (the number of words divided by the number of sentences)

ASW = average number of syllables per word (the number of syllables divided by the number of words).

Adapted from Flesch, 1973.

†See invited commentary, pp. 411–412, this issue.



We applied readability criteria to UK-based internet sites with information on schizophrenia for patients.

Method

We analysed the content of easily accessible internet sites about schizophrenia with information for patients. We used validated readability tools and generated descriptive statistics regarding readability.

Data acquisition

We chose schizophrenia for our study as it is a common, conceptually complex mental illness. There are established treatments likely to be consistent across sites. Because people with schizophrenia have problems with reading to advanced levels, clear patient information is of particular importance to them.

By using a single search term 'schizophrenia' on the Google search engine (www.google.co.uk), we identified the first 20 consecutive English language sites on schizophrenia on UK servers, ranked with the PageRankTM tool (Brin & Page, 1998). For the purpose of homogeneity, 'psychosis' was not used as a search term; some of the sites accessed using this search term dealt exclusively with drug-induced psychosis. The aim of the study was to analyse the syntax and vocabulary of the written communication about a specific information set, rather than broadly overlapping information sets, therefore the search term had to be as specific as possible. Websites that did not contain patient information (e.g. specialist journal articles) were excluded. The search was filtered for language; HTML coding, internet links and figures were stripped from the original pages to produce a textonly version of the site.

Analysis of readability

Website information was imported into Microsoft Word and analysed using the Flesch Reading Ease and Flesch-Kincaid Grade Level scoring systems (Flesch, 1973). These are widely used validated tools which assess readability based on the syllabic and sentence structure of the text. Complexity of content is not considered. The reading ease scale ranges from 0 to 100, with specific intervals categorised from 'very easy' (90–100) to 'very difficult' (0–29). The Flesch-Kincaid Grade Level corresponds to the level a person having completed a specific US school grade would be able to read.

Statistical analysis

Flesch Reading Ease and Flesch-Kincaid Grade Level scores for the 20 websites were exported to SPSS 11 for Windows to generate descriptive statistics. The distributions were normal and the mean of each was calculated. The reliability of the assessment using the Flesch Reading Ease and Flesch-Kincaid Grade Level tools was assessed using Pearson's correlation coefficient.

Results

The reading ages of the sites, derived from the Flesch-Kincaid Grade Level, ranged from 9 to 16 years with a mean of 12. None of the sites had a Flesch Reading Ease score of more than 60, the lower limit for 'plain English'. One paper scored more than 50, which translates as 'fairly difficult', 55% were 'difficult' and 40% 'very difficult'. The strong negative correlation between the scoring systems (Pearson=-0.789) supports the reliability of these results. These levels are well above the estimated reading capabilities of the UK population.

Discussion

Our results show that although easily accessible, internet-based information about schizophrenia is not easily readable. A higher-than-average educational standard in literacy is required to understand the complex vocabulary and syntax used. The information was aimed at the mean reading age of 12, which is above the average UK reading age as estimated by PRODIGY. The sites analysed in this paper came from a broad range of organisations, including patient support groups, public broadcaster-based health information sites, commercial health information sites and professional bodies.

The internet, being accessible and anonymous, is an ideal vehicle for the provision of mental health information both to patients and the public. However, its potential can only be tapped if the information produced is readily understandable. Although the context and methods of explanation can make a text better understandable, readability is a necessary condition for a text to be understood and it does not depend on the context. Given that literacy skills, vocabulary and syntax comprehension in people with schizophrenia are impaired, information on the illness has to be as easily readable as possible. Mental health professionals providing internetbased information should seek to improve its readability, for example by using shorter sentences and words, active rather than passive voice, and simpler, more common words (Horner et al, 2000). These can also reduce the chance of cultural bias in understanding (Givaudan et al,

One way in which the readability of internet sites can be improved and assessed as such is via accreditation by internet health information quality organisations. Sites that have such an accreditation have been found to be significantly more readable than those which do not (Pothier, 2005). One of the most often prominent organisations is HONCode (www.hon.ch) which is concerned primarily with accountability and the accuracy of the information presented. The Plain English Campaign (www.plainenglish.co.uk) checks readability and has established an accreditation system. None of the websites analysed were accredited by the above organisations or any other such organisations. Mental health professionals can recommend the more easily readable, accredited websites, thus improving the benefit to patients, their carers and families.

The content of internet pages tends to change often. Considering this, clinicians should not rely on lists of recommended websites, but should assess each website themselves before recommending it to patients and carers. For example, a member of the multidisciplinary team could discuss the internet information with the service user to check their understanding.

Conclusions

Easily-accessed websites containing patient information about schizophrenia do not score well when tested for readability. This has implications for service users and the general public. Mental health professionals involved in the production of websites with medical information should adapt them to the reading skills of their potential readers.

Declaration of interest

None.

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original papers

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DAVID SHIERS AND PAUL FRENCH

Invited commentary on . . . Patient information on schizophrenia on the internet[†]

'An honest tale speeds best, being plainly told.'
William Shakespeare, King Richard III

William Shakespeare and a few well chosen words... 400 years on, the vellum may have been replaced by a computer screen but Kalk & Pothier remind us that simple messages *plainly told* still work best.

The internet offers confidential and convenient access to a depth and breadth of information previously undreamed of, underpinning an information revolution with important implications for mental healthcare. However, using the example of schizophrenia, the findings of Kalk & Pothier remind us how the language of health-information internet sites can feel obscure to the end-user. Given that many young people with psychosis may already use the internet routinely for information, this is of particular relevance to early intervention services.

Furthermore, the internet is one of a range of health information sources available to young people, a group acknowledged as finding traditional health services difficult to access. Focus groups of 11- to 19-year-olds

studied in Nottingham report that the internet was their primary general information source (Gray et al, 2005). Of 1209 Americans aged 15–24, 75% report accessing health information online. Not only did these young adults access online health information, but they seek it more often than they check sports scores, purchase merchandise or participate in a chat room (Rideout, 2002).

The Pew Internet & American Life Project provides further evidence of the impact of the internet on decision-making for those with health problems and their caregivers (Fox, 2007).

- E-patients with long-term conditions are more likely than other health seekers to go online for information about their own conditions.
- 58% of e-caregivers found the internet the single most important source of information during a loved one's recent health crisis.
- The impact of the most recent search for health information was most deeply felt by internet users who

†See original paper, pp. 409–411, this issue.