Use of the DISCERN Instrument by Patients and Health Professionals to Assess Information Resources on Treatments for Asthma and Atopic Dermatitis

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ABSTRACT

Background: As patients share in the decision-making process regarding treatments they receive, it is important that they can discriminate between reliable and unreliable sources of information about potential treatments.

Methods: In this study, health professionals and patients were asked to assess the reliability of information contained in pamphlets on treatments for asthma and atopic dermatitis using a new Japanese translation of an instrument called DISCERN. The scores given by both groups were analyzed to assess inter-rater agreement. The same DISCERN instrument was used by health professionals to evaluate websites on treatments for atopic dermatitis and the degree of inter-rater agreement was assessed again.

Results: There was a greater inter-rater agreement between health professionals than between patients. When health professionals used the instrument to evaluate websites, the final rankings given were consistent between different raters, showing good inter-rater agreement.

Conclusions: We conclude that DISCERN is useful for evaluating the reliability of medical information both in pamphlets and on the internet, although it is used more effectively by health professionals than by patients. Further studies are needed on the use of DISCERN by patients in evaluating websites containing medical information.

KEY WORDS
evaluation studies, internet, medical informatics, pamphlets, patients

INTRODUCTION

As joint decision-making between patients and doctors becomes an established part of modern medical care, there is an increasing need for patients to receive good quality information upon which to base their decisions. However, doctors have a tendency to underestimate both the amount of information that patients want to receive and the amount that they are able to process.[1] Instead of relying on doctors to satisfy their thirst for medical information, patients are increasingly turning to the Internet.

In recent years the uncontrolled explosion of information available on the Internet has led to concerns regarding its reliability.[2] Various solutions have been proposed, including evaluation of web-based information by doctors,[3,4] electronic filtering of web-based information,[5] production of reliable websites by doctors and the creation of an ethical code of conduct for providers of web-based medical information.[6]

One other approach has been to design instruments to help patients themselves to rate the reliabil-

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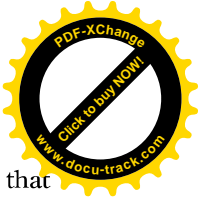Both JB and YO were involved in carrying out the research (translating, carrying out searches, distributing DISCERN instrument to participants, collecting data). YO carried out the statistical analyses. JB and YO both contributed to the writing of this paper.

ity and usefulness of the information they find on the Internet and from other sources, with the ultimate aim of patients locating and using good quality information. These instruments have received much criticism, mainly because they have not been properly validated.[4,7] Validation of the instruments presents a difficult problem, since it necessitates the comparison of the instruments with a current 'gold standard'. Owing to the subjectivity of rating information quality, no such gold standard exists. A number of 'consensus criteria'—specific assessment criteria which an instrument must include if it is to rate a website effectively—have been proposed,[8,9] but these have been criticized for their lack of detail.[10]

DISCERN is an instrument designed to help patients assess the reliability of written information on treatment choices[11] and which has attracted considerable interest since its conception. During its development and also in a number of subsequent studies, DISCERN has shown good inter-rater agreement when used by health professionals.[12-15] However, inter-rater agreement was lower when used by patients during DISCERN's initial development, and all raters in subsequent studies have been health professionals. There is little data available on how reliable DISCERN performs when used by patients and carers. DISCERN has been well received by experts in the field of web-based medical information provision, although some feel that the instrument has not been fully validated.[16] A web-based version of DISCERN is available.[17,18]

We created a Japanese version of DISCERN to be used by Japanese patients to evaluate Japanese language information on medical treatments. We then asked health professionals and carers of paediatric patients to use this instrument to evaluate written information on treatments for asthma and atopic dermatitis. In addition, we asked health professionals to use the instrument to evaluate Japanese language websites on treatments for atopic dermatitis. Our aims were: to gather more data on inter-user agreement when DISCERN is used by both health professionals and patients; to examine whether or not DISCERN is useful in enabling patients to evaluate the reliability of treatment information; and to examine the use of DISCERN in assessing the reliability of web-based information on atopic dermatitis.

METHODS

TRANSLATION OF THE DISCERN INSTRUMENT
The DISCERN instrument was initially translated from English into Japanese by a native Japanese speaker. The Japanese version was then back- translated into English by a native English speaker without reference to the original version. Any inconsistencies between the resulting English version and the original version were examined and the Japanese version adjusted appropriately. A further back-

translation from Japanese to English confirmed that these inconsistencies had been resolved.

EVALUATION OF WRITTEN INFORMATION ON ASTHMA AND ATOPIC DERMATITIS
Fifteen members of the medical staff and nine carers of nine children attending the Department of Allergy outpatient clinic at the National Centre for Child Health and Development were each given two pamphlets-one on asthma treatments and one on atopic dermatitis treatments. Participants were also provided with the Japanese version of DISCERN and instructions on how to use it, which were based upon the instructions given on the DISCERN website.[17] The medical staff and parents/carers (to be referred to as 'patients' in this paper for the sake of simplicity) then assessed the pamphlets using the Japanese translation of DISCERN.

EVALUATION OF ENGLISH AND JAPANESE WEBSITES ON ATOPIC DERMATITIS
To select potential websites for our study, we performed a search of Japanese language websites using a number of search engines (MSN, Yahoo, Nifty, Lycos, Google, Altavista, Fresheye, Excite, Infoseek, Goo and Infonav Japan) using the search term 'atopic dermatitis treatment' in Japanese. We then hand searched the first two hundred results yielded by each search engine for suitable websites. We selected twenty websites in total, ten in English language and ten in Japanese language. Some websites contained large quantities of up-to-date information on treatments for which there is a good level of evidence, and some of which contained little information or which focused on treatments for which there is little evidence. In doing so we aimed to select websites spanning a wide spectrum of quality and reliability, so as to make a wide range of scores more likely when the websites were assessed using DISCERN.

Two raters evaluated the English language websites and three raters evaluated the Japanese language websites using the DISCERN instrument. All raters were health professionals (doctors or clinical psychologists).

STATISTICAL ANALYSIS
Pamphlets
Weighted kappa is the statistical method used most often in assessing inter-rater agreement, including previous studies involving DISCERN.[11] We therefore initially performed weighted kappa analysis of our results to allow comparison with the results of previous studies. Analyses were performed on the total DISCERN scores given to the pamphlets by both health professionals and patients.

Websites
For each rater, the websites were ranked according
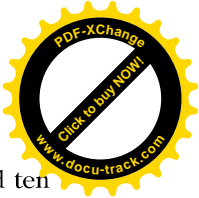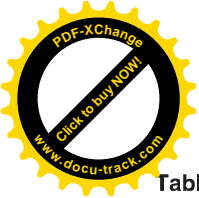
Table 1 DISCERN scores given by health professionals and patients to pamphlets on treatments for asthma and eczema

Asthma pamphlet		Eczema pamphlet	
HP[†]	P[‡]	HP	P
46	74	43	60
69	43	67	62
55	47	49	52
57	54	48	38
55	57	30	56
31	62	24	52
56	51	33	60
54	51	48	69
51	49	45	48
55		52	
58		55	
75		59	
57		50	
49		49	
51		53	

[†] HP = health professionals.
[‡] P = patients.

to the DISCERN scores given by the rater. These rankings were then compared using Kendall's W for the three raters of Japanese websites and using Spearman rank correlation for the two raters of English websites.

RESULTS

The DISCERN scores given to the two pamphlets by health professionals (HP) and patients (P) are summarised in Table 1. These DISCERN scores were used for the statistical analyses outlined above.

ASTHMA LEAFLET

For the pamphlet on asthma treatments, individual kappa values for the health professionals group ranged from −0.08 to 0.51 (average 0.15, 95% CI 0.13 to 0.18). For patients, the kappa values for individual raters ranged from −0.26 to 0.46 (average 0.08, 95% CI 0.02 to 0.13).

ATOPIC DERMATITIS LEAFLET

Inter-rater variability for the health professionals group and the patient group when rating the pamphlet on atopic dermatitis treatments was measured using weighted kappa scores. The kappa values for individual raters ranged from 0.21 to 0.44, with an average kappa score of 0.11 (95% CI 0.07 to 0.14). For patients, the kappa values for individual raters ranged from −0.03 to 0.39, average kappa score 0.16 (95% CI 0.12 to 0.20).

ATOPIC DERMATITIS WEBSITES

The DISCERN scores given by the four health profes-

sionals to the ten English language websites and ten Japanese language websites are summarised in Table 2.

Comparison of the 3 raters' DISCERN scores for the ten Japanese language websites gave a Kendall W score of 0.895 ($p < 0.01$). Comparison of the 2 raters' DISCERN scores for the ten English language websites gave a Spearman rank correlation score of 0.894 ($p < 0.01$).

DISCUSSION

FINDINGS OF PREVIOUS STUDIES

The results of the original DISCERN study gave kappa values ranging from 0.23 to 0.70 for members of an expert panel; from 0.13 to 0.63 for information providers and 0.15 to 0.50 for patients.[11] Kappa values for the DISCERN question relating to the overall quality of the information source were 0.53, 0.40 and 0.23 for these groups respectively. In other words, when assessing the overall quality of the information courses, there was a good level of agreement between experts and information providers, but only reasonable agreement between patients. However, there were higher levels of agreement between questions relating to more objective information reliability criteria. The authors stated that with training, the agreement between patients would be likely to improve, and to meet this need they have provided training sessions on how to use the instrument. The authors also stated that the patients involved in piloting the instrument became more inclined to question their assumption that some information is better than none. In conclusion, the authors stated that DISCERN could provide a framework for production, evaluation and screening of health information and enable patients to make informed treatment decisions based on good evidence.

MAIN FINDINGS OF THIS STUDY

Our study revealed a wide range of kappa values when comparing different raters' DISCERN scores for pamphlets on asthma and atopic dermatitis. This reflects the tendency for specific raters to be harsher or more generous in their scoring, which is of course a well-known phenomenon (hence the need for several independent judges at a competition). Generally, the kappa values revealed a greater degree of inter-rater agreement between health professionals than between patients.

When health professionals used DISCERN to rate and then rank websites on atopic dermatitis treatments in our study, the final rankings given were very consistent between different raters, as shown by the high Kendall W and Spearman rank correlation scores. In other words, when presented with a set of websites, it would appear that DISCERN enables a health professional to rank the websites consistently in terms of their reliability. This is even without for-
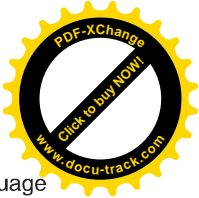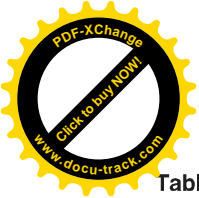
Table 2 DISCERN scores given by four health professionals to ten English language websites and ten Japanese language websites on treatments for eczema

		Average score	Lowest score	Highest score	Standard deviation
English language websites	Rater A	48.5	35	70	10.4
	Rater B	54.9	40	69	9.6
Japanese language websites	Rater B	37.9	15	61	15.4
	Rater C	47.9	28	70	15.6
	Rater D	46.9	16	71	17.2

mal training on how to use DISCERN.

WHAT THE RESULTS MEAN

Our study shows that DISCERN might not be as useful as has been suggested previously for evaluating the absolute reliability of medical information (owing to low inter-rater agreement). An important new finding is that DISCERN may be a useful means of finding more reliable medical information through the process of ranking of information sources (owing to the greater inter-rater agreement when used to rank these sources). Our study also confirms that DISCERN seems to more effective when used by health professionals, as demonstrated in previous studies.

The greater level of inter-rater agreement between health professionals may be explained by the fact that they are more familiar with the information they are rating and so will be able to assess its reliability more consistently. It is possible that there will be greater agreement between patient raters if they are more familiar with the subject material or have received training on how to use the DISCERN instrument, as pointed out by the authors of the individual study although it may not be feasible to provide patients with such training. Of note, none of the participants in this study (health professionals or patients) received formal training on how to use DISCERN, but instead they were issued with a brief summary on how to use the instrument. It is quite possible that if all participants had received training on how to use DISCERN, there may have been greater agreement between their DISCERN scores.

Interestingly, the mean DISCERN scores for English language websites were higher than those for Japanese language websites. There was also a wider distribution of DISCERN scores for the Japanese websites, implying that the quality of these websites was highly varied. However, both sets of websites were not selected randomly so no firm statements about the reliability of English language websites compared to Japanese language websites can be made from these findings.

IMPLICATIONS FOR FUTURE RESEARCH

The question as to whether or not DISCERN also enables patients to rate the reliability of websites consistently should be the subject of further study. Internet use is steadily increasing worldwide, and research has shown that two-thirds of patients using the Internet to access medical information think that this information is reliable.[19] Griffiths and Christensen examined the potential of DISCERN as an indicator of the quality of mental health websites when used by patients.[20] They found a good correlation between evidence-based quality ratings and patients' DISCERN ratings, although only three patients were included in the study. Clearly there is a need for larger-scale studies of the potential of DISCERN in the hands of patients.

CONCLUSION

In conclusion, our study provides evidence that DISCERN may be of some use enabling both health professionals and patients to assess the reliability of medical information pamphlets, although the results are more consistent when DISCERN is used by health professionals. An important new finding in our study was that DISCERN may also be useful in enabling those with medical knowledge to rank medical websites in terms of their reliability relative to each other, although further studies would be needed to show whether or not patients might be able to use DISCERN in this way.

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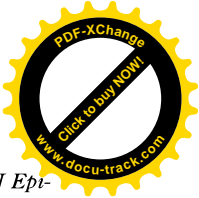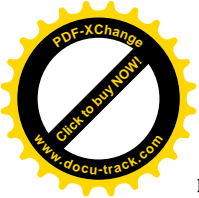
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