

# EVALUATION OF CHRONIC PAIN-RELATED INFORMATION AVAILABLE TO CONSUMERS ON THE INTERNET

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## INTRODUCTION

- 58% of Americans seek health-related information (Atkinson et al., 2009) and 39% of patients with chronic pain seek pain-related information online (Corcoran et al., 2009).
- 60% of Americans are more confident in online health information than information provided by physicians (Diaz et al., 2002).
- Given that the accuracy of online resources varies widely (Lorence & Abraham, 2008), there is a risk of client harm if they rely on unreliable information to self-diagnose or ignore physicians' treatment recommendations in favour of unsubstantiated "cures" found online.

### Quality of Online Information: Professional Evaluations

- In the most comprehensive study to date, Washington, et al. (2008) evaluated 240 chronic pain websites using self-developed criteria and concluded that online information is of poor quality and that only 3.8% of websites are of good quality. Less extensive papers about chronic pain (Corcoran et al., 2009), osteoarthritis (Maloney et al., 2004), and lumbar disc herniation (Greene et al., 2005) have drawn similar conclusions.

### Quality of Online Information: Health Consumer Evaluations

- The only known research group to ask consumers to evaluate websites found that 27 patients rated "physician approved" websites just as highly as the physicians (Gremeaux et al., 2007); However, these researchers did not evaluate consumers' ability to identify websites of poor quality.
- In another study, de Boer et al. (2007) reported that 50% of consumers believed online pain-related information to be of good quality and 1/3 based treatment decisions on such reading.

### Addressing Limitations of Current Research

- Given the rapid evolution of the Internet (Winker et al., 2000) updated periodic evaluations of the available information is necessary.
- When making such evaluations, it is important to utilize a well-validated and reliable evaluation tool. That said, past reviews have utilized various evaluation strategies that have two major shortcomings. First, the scales are not readily available to the public, which prevents health consumers from evaluating websites for themselves. Second, many of these scales include a yes/no scoring format which does not allow for the quality of the information to be fully captured.
- A better tool may be the DISCERN (Charnock & Sheppherd, 2004), an easily accessible, user-friendly Likert-scale measure. Because it is comprehensive, easy to use, and available to the general public, it appears to be a valuable instrument for conducting online evaluations.

### Purpose

- Two studies were conducted to accomplish three aims:
- Evaluate the quality of online chronic pain websites from a health-researcher perspective.
  - Evaluate the quality of online chronic pain websites from a health-consumer perspective.
  - Develop a resource for consumers that includes recommendations about high quality chronic pain sites and the evaluation of chronic pain information they encounter online.

## STUDY 1: METHODS

- Website Identification:** Commonly used pain-related search terms (i.e., pain, chronic pain, back pain, arthritis, fibromyalgia, headache, migraine, pelvic pain) were entered into the three most often used search engines. The first 50 sites from each search were evaluated.
- Website Evaluation:** Each website was evaluated with the DISCERN, which includes 16 items rated on a scale ranging from 1 (i.e., *poor quality and serious shortcomings*) to 5 (*good quality and a valuable source of information*). Each website was also evaluated for the presence of 10 general website criteria using Ilic et al.'s (2003) dichotomous Key Criteria for Website Quality.

## RESULTS

- 408 unique sites were identified. Most had some serious shortcomings and only 53 (13%) websites were of high quality. To identify the top 10 websites (**see pamphlet**), a total score was computed by summing all 16 items. Among the 53 high quality websites, the mean total score for the top 10 sites ( $M = 74.10, SD = 2.13$ ) was significantly higher than the mean total score ( $M = 64.74, SD = 5.91$ ) for the remaining 43 sites,  $t(41.5) = 8.31, p < .001$ .

Table 1. Mean scores on the 16 DISCERN items (range 1-5).

| DISCERN item   | All 408 Websites | Top 10 Websites |
|--|------------------|-----------------|
|  | Mean (SD)        | Mean (SD)       |
| 1. Are the aims clear?   | 2.50 (1.20)      | 4.10 (0.99)     |
| 2. Does it achieve its aims?   | 2.66 (1.48)      | 4.50 (0.53)     |
| 3. Is it relevant?   | 3.26 (1.34)      | 4.90 (0.32)     |
| 4. Is it clear what sources of information were used?                        | 2.12 (1.48)      | 4.70 (0.67)     |
| 5. Is it clear when the information used was produced?                       | 2.22 (1.52)      | 4.50 (1.08)     |
| 6. Is it balanced and unbiased?  | 3.42 (1.33)      | 4.80 (0.42)     |
| 7. Does it provide details of additional sources of support and information? | 2.62 (1.56)      | 4.60 (0.84)     |
| 8. Does it refer to areas of uncertainty?                                    | 2.56 (1.25)      | 4.30 (0.67)     |
| 9. Does it describe how each treatment works?                                | 2.99 (1.41)      | 4.80 (0.42)     |
| 10. Does it describe the benefits of each treatment?                         | 2.73 (1.35)      | 4.80 (0.42)     |
| 11. Does it describe the risks of each treatment?                            | 2.49 (1.34)      | 4.80 (0.63)     |
| 12. Does it describe what would happen if no treatment was used?             | 2.46 (1.28)      | 4.40 (0.52)     |
| 13. Does it describe how treatment choices would affect quality of life?     | 2.30 (1.19)      | 4.40 (0.70)     |
| 14. Is it clear that there may be more than one treatment choice?            | 3.38 (1.51)      | 5.00 (0.00)     |
| 15. Does it provide support for shared decision making?                      | 2.59 (1.30)      | 4.50 (0.53)     |
| 16. Overall quality of the publication.                                      | 2.82 (1.34)      | 5.00 (0.00)     |

- Table 2 shows the relationship between the Key Criteria of Website Quality and the Overall Quality rating of the DISCERN. As shown, sites providing direct services (e.g., a product) contained significantly poorer information than sites not providing direct services. The presence of all other criteria was associated with higher information quality.

Table 2. DISCERN ratings associated with website characteristics.

| Website Characteristic             | Number of sites with characteristic | Number of sites without characteristic | Quality score of websites with characteristic [M ± SD] | Quality score of websites without characteristic (M ± SD) | T-value | sig |
|------------------------------------|-------------------------------------|--|--|---|---------|-----|
| Sponsorship identified             | 140                                 | 268                                    | 3.07 ± 1.37  | 2.69 ± 1.31   | 2.78    | **  |
| Membership available               | 66                                  | 342                                    | 3.53 ± 1.07  | 2.68 ± 1.34   | 5.71    | *** |
| Direct Services available          | 38                                  | 370                                    | 1.31 ± 0.41  | 2.99 ± 1.28   | 5.32    | *** |
| Linked to from other sites         | 250                                 | 158                                    | 2.96 ± 1.41  | 2.59 ± 1.19   | 2.98    | **  |
| Currency of information recognized | 96                                  | 312                                    | 3.85 ± 1.09  | 2.50 ± 1.24   | 9.94    | *** |
| Updating of information recognized | 165                                 | 243                                    | 3.49 ± 1.13  | 2.36 ± 1.27   | 9.44    | *** |
| Authorship attributed              | 140                                 | 268                                    | 3.67 ± 1.08  | 2.37 ± 1.24   | 10.73   | *** |
| Referral links to other resources  | 128                                 | 254                                    | 3.49 ± 1.22  | 2.50 ± 1.28   | 7.18    | **  |
| External endorsement of the site   | 124                                 | 284                                    | 3.48 ± 1.23  | 2.53 ± 1.28   | 6.75    | *** |
| Referencing of evidence            | 86                                  | 322                                    | 3.80 ± 1.14  | 2.56 ± 1.26   | 8.76    | *** |

\*\* p < .01; \*\*\* p < .001

## STUDY 2: METHODS

- Participants:** 21 individuals with chronic pain were recruited from clinics, chronic pain message boards, and advertisement websites in Newfoundland, Nova Scotia, and New Brunswick. Participation took 2 hours and participants received an honorarium of \$25.
- Website Evaluation:** 15 websites (a combination of the 10 highest scoring and 5 mediocre websites) were evaluated. Each participant evaluated 5 websites using the DISCERN. They were also asked a number of open ended questions regarding (i) their opinions of the DISCERN, (ii) the type of chronic pain information they seek, and (iii) positive and negative aspects of the websites.

## RESULTS

- Each site was evaluated seven times. Participants tended to highly agree on the overall quality of the 15 websites (ICC = .775), while the level of agreement regarding specific aspects of the site was quite varied (ICC = .063 – .883). Compared to the mediocre sites ( $M = 2.83, SD = 0.82$ ), the 10 highest scoring sites identified by the researchers ( $M = 3.97, SD = 0.45$ ) were also rated significantly higher by the consumers,  $t(5.21) = 2.90, p < .05$ .
- Participant responses to the open-ended questions also elicited a number of consistent themes: (i) the DISCERN is a very useful evaluation tool but may be too time-consuming for the average consumer; (ii) consumers tend to seek unbiased information about the treatment of chronic pain, including alternative treatments; and (iii) websites covered treatment options well but coverage of associated risks was limited.

## GENERAL DISCUSSION

- Consistent with past research, chronic pain sites tend to be of poor quality, raising the possibility that patients are basing treatment choices on faulty information. Furthermore, the findings suggest that Key Criteria of Overall Website Quality can be used to differentiate between sites with high quality information and low quality information.
- Health consumers can differentiate between sites of high and low quality using the DISCERN. Furthermore, the findings showed that consumers' overall ratings of each site was fairly consistent, suggesting different consumers will rate a site similarly if using the DISCERN.
- Overall, a number of recommendations can be drawn from these studies. Consumers should (1) consider the top 10 websites provided in the pamphlet; (2) utilize the DISCERN to evaluate website quality, though the Key Criteria of Website Quality may be used as a basic screening tool; (3) utilize websites that are endorsed or sponsored and provide references and updated information; and (4) avoid websites providing a direct service or selling a product.

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